



**The Development and Practice of Health -  
Literacy in Patients with a Long-term  
Health Condition through Self-directed  
Learning, Patient Education, and Social  
Interaction**

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**Thesis submitted for the degree of  
Doctor of Philosophy  
at Cardiff University**

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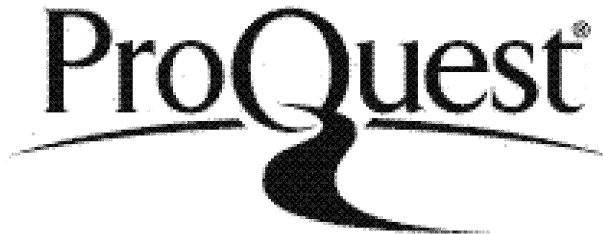
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## ***Abstract***

This thesis aimed to explore the ‘evolving concept’ of health literacy. This was done through a literature review and using empirical research methods to investigate how people with a long-term health condition develop and practice health literacy in the context of managing their health, through interactions with healthcare professionals and making health decisions. The thesis also aimed to investigate how that patient education might promote the development of health literacy.

A longitudinal qualitative research design, (including interviews and observations) was used to collect and analyse participants’ personal accounts and actions that reflect their health literacy skills, practices and actions. Data analysis using a framework approach explored health literacy using a thematic framework that allowed for current and new descriptions of health literacy to be considered.

Existing categories of health literacy were extended (e.g. interactive health literacy), and new categories explained (e.g. health risk literacy) in relation to how participants practised them in the various health contexts that they encountered. Health literacy developed along a trajectory that included the development of knowledge, health literacy skills and practices, health literacy actions, abilities in seeking options and informed and shared decision making opportunities. Motivations and barriers to developing and practising health literacy skills were personal to participants’ characteristics and also created by health professionals.

Health literacy was also an outcome of informal and formal learning opportunities and was distributed through social networks. Participants drew on health literacy skills made available by others as a personal resource. Patient education programmes promoted the development of health literacy through formal and informal learning opportunities that were presented within the time of the programme.

The findings in this thesis can inform the development of new health literacy measurement tools and for the design and implementation of new and innovative health literacy-based patient education interventions.

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## ***1.0 Introduction to thesis***

This thesis will explore the concept of 'health literacy', how it is experienced by patients with a long-term condition, and how it relates to involvement in healthcare processes (including decision-making), how it might develop in different health contexts and through patient education strategies. The thesis is based on qualitative research methods including interviews and observation work with three groups of participants who attended patient education programmes and one group of participants who learned about their condition through other methods.

This introductory chapter aims to provide:

- A brief description and an overview of literacy and an introduction to the concept of health literacy.
- An overview of the disease specific and self-management patient education programmes that provided the research contexts featured in this thesis.
- A brief discussion of patient education and health literacy in relation to empowerment.
- A brief overview of patient involvement in healthcare decisions and an introduction to the concept of shared decision-making.
- An overview of UK health policies that are important to patient education, patient involvement in healthcare (including decision-making) and to health inequalities.
- An overview of the scope of health literacy research in the UK and the current UK health literacy research agenda.

The chapter will also introduce the rationale for the thesis and introduce the aims and objectives of the research before giving a brief overview of the thesis.

## 1.1 Literacy and health

Literacy is broadly defined as:

“An individual’s ability to read, write and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and develop one’s knowledge and potential.” (National Literacy Act of 1991, US).

The National Adult Literacy Survey (United States) (Kirsch et al. 1993) estimated 90 million adults as having inadequate literacy skills to meet the needs of the 21<sup>st</sup> century. Since then, a later survey (National Assessment of Adult Literacy 2003) indicated that an estimated 29% of Americans (62 million adults) have *basic literacy levels* (e.g. skills necessary to perform simple everyday literacy activities). A further 14% (30 million) were estimated to have *below basic skills* (e.g. the most simple and concrete literacy skills used in everyday life).

In the UK, the Department for Education and Skills found that 16% of adults performed at entry level three or below on a literacy assessment (DfES 2003). A person scoring at entry level three is able to understand short straightforward texts on familiar topics accurately and independently. In Australia, data from the Adult Literacy and Life Skills Survey showed 47% (15 million adults) had basic or below basic literacy skills.

Concerns about literacy levels in the above populations (and others) have raised concerns about people’s abilities to function in health contexts. Although people with basic health literacy skills may be able to meet demands within their homes, workplace and community, their level of literacy may not be sufficient to gain a good understanding of health information, access health services, and participate in making health decisions. Hence, people with the lowest literacy skills may struggle even more with health information and services.

### Definitions of health literacy

The concept created to describe literacy in health contexts is known as ‘health literacy’. However, the terms literacy and health literacy are often used interchangeably when referring to issues surrounding literacy and health. Earlier

definitions of health literacy describe it as a set of literacy abilities related to health (e.g. Parker et al 1995). However, more recently there have been a growing number of definitions that describe it as more than the application of reading, comprehension and writing skills to health information, and that a range of skills are needed that determine individuals' understanding of health and healthcare and their effectiveness in using healthcare services (e.g. Nutbeam 1998; Zarcadoolas et al. 2003; Kickbusch and Maag 2008). Chapter two provides a review of health literacy definitions, conceptualisations and measurements.

The definition of health literacy that was chosen as most appropriate to guide the development of this thesis is that of Kwan et al. (2006) because it reflects the skills and practises needed for seeking and engaging with health information, it acknowledges the importance of different 'health contexts' and is concerned with health throughout one's life-time.

**"People's ability to find, understand, appraise and communicate information to engage with the demands of different *health contexts* to promote health across the life-course".**

**Kwan et al. (2006)**

The implications of poor literacy and poor health literacy are that people may not be able to develop skills that enable them to seek, engage with or use health information in ways that promote health. Research evidence on health literacy and health outcomes has suggested that it is a key determinant of health (see chapter two for a review of the evidence).

### ***1.2 Health literacy skills and practices***

A range of practical skills are involved in health literacy (i.e. listening, speaking, arithmetic, problem solving, and decision making). These skills determine individuals' understanding of healthcare, the effectiveness of their use of healthcare services and abilities in seeking, comprehending and using health information in ways that enables them to participate in healthcare processes. The actions that people carry out requiring skills associated with health literacy are described in this thesis as "health literacy practices". Examples of health literacy practices are featured in the

following table (Table 1) of skills needed for health (adapted from the Institute of Medicine report on health literacy, 2004).

**Table 1.1 Skills Needed for Health (IOM 2004)**

Health-Related Goal	Tasks (practices)
Promote and protect health and prevent disease	<ul style="list-style-type: none"> <li>• Read and follow guidelines for physical activity</li> <li>• Read, comprehend, and make decisions based on food and product labels</li> <li>• Find health information on the internet or in periodicals or books</li> </ul>
Understand, interpret, and analyze health information	<ul style="list-style-type: none"> <li>• Determine health implications of a newspaper article on health issues</li> <li>• Determine which health websites contain accurate information and which do not</li> <li>• Understand the implications of health related initiatives in order to vote</li> </ul>
Apply health information over a variety of life events and situations	<ul style="list-style-type: none"> <li>• Determine and adopt guidelines for increased physical activity at an older age</li> <li>• Read and apply health information regarding childcare or eldercare</li> <li>• Read and interpret safety precautions at work; choose a health-care plan</li> </ul>
Navigate the healthcare system	<ul style="list-style-type: none"> <li>• Understand printed patient rights and responsibilities</li> <li>• Find one's way in a complicated environment such as a busy hospital or clinic</li> </ul>
Actively participate in encounters with healthcare professionals and workers	<ul style="list-style-type: none"> <li>• Ask for clarification , ask questions</li> <li>• Make appropriate decisions based on information received</li> <li>• Work as a partner with care providers to discuss and develop appropriate regimen to manage chronic disease</li> </ul>
Understand and give consent	<ul style="list-style-type: none"> <li>• Comprehend required informed consent documents before procedures or for involvement in research studies</li> </ul>
Understand and advocate for rights	<ul style="list-style-type: none"> <li>• Request access to information based on patients rights documents</li> <li>• Determine use of medical records based on the privacy act</li> <li>• Advocate on behalf of others such as the elderly or mentally ill to obtain needed care and services</li> </ul>

### **1.3 Health contexts**

Health literacy is often discussed in relation to 'health contexts'. The Institute of Medicine use the term "health contexts" to reflect the range of situations and activities relating to health (IOM 2004). Health contexts are not necessarily situated in healthcare settings such as primary care services, hospitals, clinics and pharmacies; they may also be in the work place, at home, community groups, and educational settings. Thus, they can be located in any place or situation that a person needs to

engage with, or communicate, health information. This thesis will use the term health contexts to refer to the *scenarios* (e.g. consultations with a health professional, conversations with friends or family, collecting a new medication from a pharmacist) and *settings* (e.g. primary care, hospitals, clinics, pharmacies, education settings, community settings, in the home or workplace) in which *activities related* to health (or health literacy practices) take place.

#### ***1.4 The management of chronic disease and health literacy***

The prevalence of chronic disease in the UK is 60% among the adult population and 75% among people over 75 years; with 45% of those with chronic disease having more than one condition (Department of Health 2004). The self-management of chronic disease is a key policy issue in the UK. The 1999 White Paper Saving Lives: Our Healthier Nation acknowledged that people with long-term health problems are skilled at recognising the warning signs when their symptoms are getting worse (Department of Health 1999). The NHS Plan (Department of Health 2000) set out a vision in which the NHS will become a resource which people routinely use to help look after themselves (Department of Health 2000). Self Care – A Real Choice (Department of Health 2005) argued that there is growing evidence that supporting self-care can help to improve health and quality of life, leading to an increase in patient satisfaction and a reduction in the use of health services.

For some chronic diseases (such as arthritis), self-management has been suggested to be a way of facilitating control over pain, participation in decisions about treatment, and enabling people to achieve a sense of control over their lives (Barlow et al. 2000; Lorig and Holman 2004). However, research involving patients with chronic disease (such as diabetes and asthma) has suggested that inadequate health literacy is associated with poor self-management (Ho Tang et al. 2007; Williams et al. 1998).

#### ***1.5 Patient and self-management education***

Patient education programmes have been successful in improving the management of chronic disease and health outcomes. Asthma programmes have been found to improve knowledge, self-management skills and decrease morbidity, (Hindi-Alexander 1987; Wilson et al. 1993) and hypertension and diabetes education programmes have been found to enhance compliance with health care appointments

and medications (Mullen et al. 1992; Padgett et al. 1988). This thesis includes participants who participated in a structured diabetes education programme (X-PERT Programme), a generic self-management programme (Expert Patient Programme), and a cardiac rehabilitation programme. This section will provide some background on these programmes and relevant research evidence.

### *1.5.1 Structured patient education for diabetes in the UK*

The X-PERT programme is a structured patient education programme for patients with diabetes. It is part of the National Service Framework for Diabetes which recommends structured education as an important part of supporting self-care within a diabetes service. It is delivered at a local level by a health professional and involves six weekly sessions at a community venue, each lasting two hours. The programme is aimed at developing skills and building confidence to enable patients to make informed decisions. Two theoretical models underpin the X-PERT programme; (1) “empowerment”, where patients use their innate ability to gain some mastery over their diabetes (Anderson and Funnell 2000), and (2) “discovery learning”, where the learner uses tools and information to gain knowledge through discovery.

### *Research*

A randomised controlled trial of the X-PERT programme found that participation in the programme led to improved glycaemic control, reduced requirement for diabetes medication, reduced body weight, BMI and waist circumference, lowered total cholesterol levels, increased intake of fruit and vegetables, increased knowledge of diabetes, self-empowerment, psychosocial adjustment, and readiness to change and setting and achieving goals. The effectiveness of the programme is suggested to be due to a combination of the theoretical underpinning of the programme, the skills and motivation of the educator, peer support and group work, visual aids, shared health records and goal setting (Deakin 2006). This thesis will feature some participants who attended an X-PERT programme in Wales.

### *1.5.2 The Expert Patient Programme (EPP)*

The Expert Patient Programme is a generic community-based lay-led self management programme for patients with a long-term health condition. It is an adaptation of the Chronic Disease Self-Management Programme (CDSMP) developed

in the US by Kate Lorig and colleagues. The UK programme was developed alongside the publication of a 2001 Department of Health report *the expert patient: a new approach to chronic disease management for the 21st century*, (Department of Health 2001). The EPP has been implemented in England with the support of the Department of Health, and in Wales with the support of the Welsh Assembly Government. This thesis will feature some participants who attended an EPP course in Wales.

### *Research evidence on the effectiveness of generic self management education*

#### *Quantitative studies*

Generic lay-led self-management programmes have shown significant reductions in health distress, and improvements in self-efficacy, and self-rated health and energy/fatigue (Lorig et al. 1999) in a US study. A UK study, however, only showed small to moderate increases in self efficacy and reductions in anxiety and depressed mood (Wright et al. 2003). Evidence from the US showed that compared to a waiting-list control group, participants who took part in chronic disease self-management programmes had fewer hospitalisations and shorter stays in hospital and improved communication with their physician but not fewer visits to a physician (Lorig et al. 1999). A longitudinal study to follow up the randomised control trial reported fewer visits to the emergency room and physicians each year over a two year period (Lorig et al. 2001). However, an evaluation of the Expert Patients Programme (EPP) has shown no real impact on routine health service use but some reductions in inpatient use (Kennedy et al. 2007). Another study found no reduction in primary care visits and no improvement in communication with a physician; however it is important to note that this study included a minority ethnic group (Bangladeshi) (Griffiths et al. 2005).

#### *Qualitative studies*

Qualitative research is useful to explore and analyse the processes that lead to the observed outcomes of self-management education. One qualitative interview study has explored the relationship between self-management education (operated by the EPP) and the utilisation of health services in the UK. The results suggest that the biographical and social contexts relevant to living with a long-term health condition, pre-existing health service utilisation and established relationships with health



professionals are important to understanding the impact of self management education (Gately et al. 2007). For example, self-efficacy was improved when people felt better able to cope because they were able to make social comparisons between themselves and others and identify with others who share their experience of living with a long-term condition. However, rather than initiating behaviour change as a result of participation, the course reinforced the salience of pre-existing self-management strategies. The lack of change in healthcare utilisation was suggested to be because patients already had established routines of consulting; service use tends to be influenced by the supply side; and the fact that the course is distinct from advice and actions provided by healthcare professionals. In terms of communications with healthcare professionals reports were mixed; communication styles had not changed for some, whilst others felt the programme had helped improve interactions with health professionals (Gately et al. 2007).

An observational study of the EPP (Wilson et al. 2007) revealed that some participants felt that after participating in the EPP they had increased confidence in communicating with doctors, but this was tempered by no change in the way doctors dealt with them. Some doctors negated or sidelined patients' new-found 'expertise'. This may have had a negative impact on the exchange of potentially relevant information and the potential for shared decision-making (Wilson et al. 2007). Kennedy et al (2007) suggest that the exact mechanisms by which the EPP achieves its effects are unclear. For example, it is not clear whether outcomes are due to the structured nature of the course or non-specific factors such as the group experience. Qualitative research may be useful to explore the social interactions involved in participation in self-management programmes (i.e. interactions between participants and between participants and programme facilitators).

### *1.5.3 Cardiac rehabilitation programmes*

Comprehensive cardiac rehabilitation offers patients with coronary heart disease a long-term programme involving medical evaluation, prescribed exercise, cardiac risk factor modification, education and counselling. Patients are encouraged and supported by a multi disciplinary team of health professionals to maintain optimal physical and psychosocial health (Beswick et al. 2004). In the UK Cardiac rehabilitation usually comprises four phases. The first phase involves counselling with education and

psychological support in hospital, the second phase involves telephone contact and home visits with a nurse to give advice on everyday activities and light exercises. Phase three is an education and exercise programme delivered in an outpatient setting and typically lasts for 6-8 weeks, and phase four offers cardiac support to those who are continuing to exercise and adhere with lifestyle changes (Beswick et al. 2004).

The Fifth Report on the Provision of Services for Patients with Coronary Heart Disease states that in the UK patients must have access to rehabilitation when required, for example after a heart attack, cardiac surgery and intervention (Hall et al 2002). The National Service Framework for Coronary Heart Disease (NSF-CHD) in England includes patients who have survived acute myocardial infarction and those who have undergone a coronary artery bypass graft (CABG) or percutaneous transluminal coronary angioplasty (PTCA) as a priority for cardiac rehabilitation (Department of Health 2000). In Wales cardiac rehabilitation is provided to those who have an episode of acute coronary syndrome, some of whom will have undergone CABG or PTCA (National Assembly for Wales 2001). Some participants included in this thesis attended a phase three cardiac rehabilitation programme in Wales.

### *Research*

Research on the effects of a cardiac rehabilitation programme on cardiovascular, psychological and social functioning has reported more efficient cardiovascular functioning (resting heart rate, resting diastolic blood pressure, treadmill exercise performance, exercise heart rate, exercise systolic blood pressure), better understanding of heart disease, better understanding of and reported compliance with treatment recommendations, more positive self-perceptions (health, body concept, self-concept, progress toward goals), and better psychosocial functioning (e.g., decreased employment related stress, more active use and enjoyment of leisure time, more physical and sexual activity). These benefits were evident not only just after rehabilitation, but also 4 months later (Rovario et al. 2004).

## ***1.6 Empowerment***

There are many definitions and meanings of the term empowerment. In a similar way to the concept of health literacy, the concept of empowerment varies from researcher to researcher. The meaning of empowerment can be dependent on the context in which it is being used (Wallerstein and Bernstein 1988). In healthcare contexts empowerment has been described as an absence or decline of powerlessness, helplessness, alienation, victimisation, oppression, subordination and paternalism (Gibson 1991). Empowered patients are said to be more in control of their health and encounters with medical professionals (Johnston Roberts 1999).

### ***Empowerment and education***

Paulo Freire (1970) viewed empowerment in the education context as both a process and an outcome. Empowerment becomes a process during educational interventions aimed at developing critical thinking and autonomous actions. When self-efficacy is experienced as a result of the empowerment process then it becomes an outcome.

### ***Empowerment and health education***

Freire's (1970) ideas about empowerment have been applied to the field of health education to form a theoretical basis for the development of health education strategies. Empowerment is said to be a process that runs alongside patient education and at the same time can be an outcome of patient education (Anderson and Funnel 2010). The goal of an empowerment approach to health education is to enhance patient autonomy and expand freedom of choice (Feste and Anderson 1995). Its purpose is to prepare people to function effectively as autonomous members of their healthcare team and to be competent providers of their own daily healthcare. Patients who participate in empowerment education strategies are helped to develop self-awareness about their health values, needs and goals and to examine the emotional, social, cognitive and spiritual parts of their lives in relation to decisions about their own health. (Feste and Anderson 1995).

Skelton (1994) is sceptical of 'empowerment' approaches to health education and suggests that they are disguised forms of paternalism. For example, 'empowerment' in such contexts may be more involved with getting patients to behave in ways that the 'expert' (health professional) proposes, but at the same time allowing the patient

to think that the changes are their own idea (Skelton 1994). Critics of the EPP have suggested that it promotes medical power through its reliance on the medical model and its use of the language of disease and paternalism within the programme (Davidson 2005, Fox et al. 2005). The rigid and scripted delivery and support of the medical model may bias it towards a form of health education that is based not on an empowerment approach but a more traditional *compliance approach to healthcare*; an approach that persuades and prepares patients to carry out recommendations made by health professionals (Raymond 1984). Furthermore, Rogers (2009) suggests the EPP seems to attract people with values and behaviours that are congruent with policy and disregards those who do not hold such values. Gately et al. (2007) suggest that people who prefer to normalise chronic illness and its management rather than becoming involved in active engagement in health activities and self-surveillance and reflexivity are not embraced by the programme.

### *Health literacy and empowerment*

The effective use of health information is said to be critical to 'empowerment' (Nutbeam 1998). Current philosophies and descriptions of patient empowerment appear to necessitate at least a moderate degree of health literacy. For example, one philosophy of empowerment suggests that in order to be healthy, people must be able to make changes in their personal behaviour, social situations and organisations that influence their lives (Feste and Anderson 1995).

Patients with limited health literacy may have a lack of knowledge and understanding of health that prevents them from being self-determined or autonomous (Erlen and Erlen 2004). Furthermore, their capacity to make healthcare decisions may be constrained by their limited health literacy skills. There seems to be an ethical tension surrounding the decision-making of patients with limited health literacy that may limit empowerment. They may be more vulnerable to poor health outcomes if they are not fully supported by healthcare professionals when making their healthcare decisions (Erlen and Erlen 2004). They may also be more vulnerable to the control of healthcare professionals because they have limited understanding of what they are reading or what is being communicated to them in consultations (Erlen and Erlen 2004).

Although it can be argued that it is a patient's right to choose whether or not to follow a treatment regimen, their choices are based on their knowledge and understanding of

health (Beauchamp and Childress 1994). Thus, if they have low health literacy then their knowledge and understanding are limited and making informed decisions may become difficult.

### ***1.7 Patient involvement in making health decisions***

Modern chronic disease care and the successful self-management of chronic disease necessitate patients to be actively involved in their care and require healthcare professionals to partner with patients to promote successful outcomes (Schillinger and Davies 2005). With some chronic health conditions the benefits of treatment clearly outweigh harms (O'Connor 2003). However, with other chronic health conditions there may be insufficient evidence about treatment effects to draw conclusions about the ratio of benefit to harm, or the ratio may be known but is affected by patients' values (O'Connor 2003). When several treatment options are known to be effective in producing different types of health benefit and also possible harm, patients' decisions and treatment preferences are important (Kassirer 1994). Thus, there comes an opportunity for some negotiation between a healthcare professional and a patient regarding a choice of treatment.

A concept of shared decision-making has been devised, where patients collaborate with a healthcare professional to arrive at an agreed treatment decision. Shared decision-making is an interactive process by which doctors and patients jointly participate in a treatment decision-making process and come to some negotiation as to which treatment is implemented (Charles 1997). Patient involvement in shared decision-making is widely advocated by the health profession for a number of reasons; firstly, it has been accepted as an ethically appropriate form of practice that promotes veracity and patient autonomy (Ashcroft et al. 2001). Secondly, it has been associated with improvements in the standards of health care (Coulter 1997), and thirdly, it been associated with adherence to treatment and improved health outcomes (Greenfield et al. 1985).

Three elements of shared decision-making have been proposed. Firstly information exchange, where patients and physicians share information regarding their symptoms and available options for treatments. Secondly, deliberation takes place where treatment preferences are expressed and discussed. Finally, a decision on which

treatment to implement is reached. In order to arrive at a shared decision the input of both the patient and the physician are equally important.

### *Research*

Research has shown that shared decision-making is inconsistently achieved in practice, (Braddock et al. 1999) partly because practitioners do not always implement it in their practice and partly because patient preferences for involvement in shared decision-making tend to vary (Charles et al 2003; Vick and Scott 1998). Although it has been reported that physicians are more likely to facilitate shared decision-making with patients with chronic diseases (Gotler et al. 2000) a significant amount of variability in rates of facilitation have been identified (0-79%) (Gotler et al. 2000). A number of facilitators and barriers to physicians' implementation of shared decision-making in clinical practice have been identified. Facilitators were: motivations of healthcare practitioners, perceptions of improved outcomes for the patient, and perception that it would lead to better healthcare processes. Constraints on time were the most frequent barrier, and then lack of agreement with aspects of shared decision-making, and lastly a perception that shared decision-making is not applicable for a given patient (Gravel et al. 2006). Patients' preferences for involvement in medical decision-making have only partly been explained. For example, some suggested factors are: demographic variables (e.g. age, educational attainment, class, occupation and income), illness experience, health status, type of decision, preference for information, and relationship with healthcare practitioner (Say et al. 2006).

There are a small number of studies that have investigated health literacy in relation to shared decision-making (e.g. Kim et al. 2001; Mancuso & Rincon, 2006). These studies suggest that poor health literacy is a barrier to participation in shared decision-making. These studies will be discussed more in chapter two.

### *1.8 Health inequalities and health literacy*

People in different social circumstances experience differences in health, well-being and length of life. Inequalities in health are created through inequalities in society such as the conditions in which people are born, grow up, live and work (Marmot Review, 2010). Other factors that are suggested to determine health and contribute to health inequalities are: ethnicity, age, education and adult literacy. Health literacy is

also a recognised social determinant in health and is a concern for those with an interest in reducing health inequalities (Coulter and Ellins 2007). The Skilled for Health Programme (England) is targeted at improving health through adult literacy and learning programmes. The programme aims are: to contribute to reducing health inequalities by improving health among those communities which demonstrate the worst health outcomes, and to enhance the ability of individuals within those communities to make informed decisions about health and well-being in a variety of different settings. The Department of Health has adopted an interest in health literacy as a barrier to health and acknowledges that it should be addressed in strategies to reduce health inequalities. The *Marmot Review: Fair Society, Healthy Lives* (2010) has drawn attention to the Expert Patient Programme as one strategy for reducing health inequalities and improving both self-management and health literacy.

### ***1.9 The UK (England) policy context and health literacy research agenda***

Recent health policies have begun to address some of the issues surrounding the UK's public access to and engagement with health information, development of self-management skills for chronic disease (through education) and patient choice. In recent years the Department of Health has been committed to improving the quality of patient education and health information. The Acheson Report (Acheson 1998) on health inequalities influenced efforts to improve the public's knowledge and access to health information. A White Paper *Saving Lives: Our Healthier Nation* (Department of Health 1999) aimed to address health inequalities through improving public and patient health education and access to information. Government strategies to address these include *NHS Direct* (a telephone information and advice service), the *Expert Patient Programme (EPP)*, and more recently *NHS Online* (a web resource for patients).

The notion of patient choice in their healthcare and treatment is a key focus of the National Health Service. A NHS white paper called *Choosing Health* emphasised the importance of informed patient choice in healthcare options (Department of Health, 2004) and more recently, a new White Paper called *Equity and excellence: Liberating the NHS* has developed a set of strategies to help put patients first. Some of these include:

- Making shared decision-making the norm, with a focus on “no decision about me without me”.
- Allowing patients to have access to all the information they want, make choices about their care and have increased control over their care records.
- Patients will have a choice of their health care provider including GP practice, consultant team, maternity services and a choice of treatment.

(Department of Health, 2010)

There seems to be a paradox where patients currently are permitted greater access to health information than ever before (e.g. through health based internet sites and access to online medical journals and health forums etc.) but social disparities may affect their ability to access, use and understand such information (Protheroe et al. 2008). Coulter and Ellins (2007) have recognised health literacy as essential to patients’ involvement in their care. However, offering patients more participation in decision-making and choosing a suitable healthcare provider may create a similar paradox where social disparities might limit some patients’ understandings of patient choice and affect participation in healthcare processes. Protheroe et al. (2009a) suggest that health literacy should be more overtly accounted for in policy implementation strategies aimed at participation in healthcare. They argue that only reaching a subset of patients with higher literacy skills and greater confidence in the system, and excluding interventions to address low health literacy, may well result in increased health inequalities.



*UK research agenda*

A UK report on health literacy for the National Consumer Council recommends that research is required in order to understand the challenges of health literacy across the healthcare system, the variation among different groups and the impact of inadequate health literacy on access to healthcare (Sihota and Lennard 2004). The report focuses on information seeking and shared decision-making and concludes that people need information, knowledge and understanding in order to exercise greater control over their health. The scope of health literacy research in the UK is small at present. However, a national group of researchers plans to develop a strategic framework for health literacy research in order to address health inequalities. Some of the key objectives of the National Health Literacy Group are to develop a critical mass of stakeholders, to bring researchers together to develop ideas for research, and to build an evidence base of health literacy research in the UK (<http://www.healthliteracy.org.uk>). Members of the group have also been involved in setting an international collaborative research agenda for health literacy research with members of the North American Primary Care Research Group. Topics of debate included: refining health literacy definitions and conceptual models, health literacy measurement and assessment tools, and developing a collaborative international research agenda (Protheroe et al. 2009b).

### **1.10 The rationale for the thesis**

The justifications for this thesis are based on an initial overview of the health literacy literature and the findings of literature review (Chapter 2), and include the following:

1. There is no consensus on the meaning of health literacy within the literature and there is scope to develop the concept of health literacy and health literacy measurements further.
2. There are few qualitative studies that explain health literacy practices.
3. Little is known about how people become health literate and how health literacy is developed and maintained over a person's lifetime.
4. There is insufficient knowledge about how health literacy may affect decision making regarding health treatments and healthcare.
5. Health literacy is known to be a factor in outcomes of some patient education and self-management programmes but there is insufficient knowledge about how patient education programmes may contribute to health literacy.

### **1.11 Thesis aims and objectives**

The main aims of this thesis are to determine what health literacy is from the perspective of patients living with a long-term condition, how they practise health literacy and how they develop it over time. Further aims were to identify barriers to health literacy and to investigate whether and how health literacy can be developed through group-based patient education programmes. The thesis objectives were:

- 1. To undertake a historical and theoretical review of the literature on health literacy.**
- 2. To describe the meaning and experience of health literacy skills for patients with a chronic condition across different health contexts.**
- 3. To describe how patients' understandings and abilities concerning their health and their health literacy practices compare with given definitions of health literacy.**
- 4. To describe how patients become health literate with their condition and how they experience healthcare communication (including information exchange and informed/shared decision-making).**
- 5. To describe how health literacy may affect patients' experiences of using healthcare services in various contexts and identify possible facilitators and barriers to the development and use of health literacy skills.**
- 6. To describe the range of health literacy practices that may be developed through patient education and relate them to definitions of health literacy.**
- 7. To describe processes involved in the development of functional, interactive and critical health literacy for patients who participate in self management programmes and how these processes differ across groups of patients.**

### ***1.12 Overview of the thesis***

Following this introductory chapter there are seven chapters:

#### ***Chapter 2- Review of the literature***

The literature review is based on the rationale and the research aims and objectives set out here. The chapter has four parts. Part one reviews current health literacy definitions conceptual models and measurements. Part two covers empirical research evidence on health literacy and health outcomes. Part three covers health literacy and patient involvement in healthcare consultations. Part four reviews educational strategies aimed at improving health literacy. The chapter will draw conclusions about how definitions and measurements of health literacy have shaped the research methods and findings on health literacy and health outcomes.

#### ***Chapter 3-Methods***

This section of the thesis will explain how the study sample was recruited, how the study was conducted and provide the reader with an understanding of the context in which the thesis findings are set. It will discuss the methods of data collection and the value of them, and describe the method of data management and data analysis that enabled the interpretation of participants' responses to help conceptualise health literacy from a patient perspective.

#### ***Chapter 4-Study participants***

This chapter introduces the participants in the research. Each participant is described in terms of their family, educational and occupational background. Some of their personal characteristics, health experiences and information seeking behaviours that are relevant to the aims and objectives of the thesis are described. Understanding the background, characteristics and health experiences of participants helps appreciate how the findings relate to the personal contexts of each participant.

#### ***Chapter 5- A health literacy framework based on patient experiences***

This chapter presents *new* and *extended* categories of health literacy, based on how participants practised health literacy skills across a range of health contexts. Some of the health literacy categories included in this chapter have been established in the health literacy field but have been expanded in the thesis to reflect the health experiences of patients with a long-term condition. New health literacy categories in

this chapter have been devised based on the experiences of participants; some partly resemble areas of literacy that have not been well explained within health contexts.

*Chapter 6-A health literacy pathway towards better engagement and use of health-care information and services*

This chapter presents a Health Literacy Pathway Model to show how health literacy develops along a trajectory that involves informed decision making and shared-decision making. The model is based again on how some participants developed and practised health literacy and became more active within healthcare consultations and in decision-making processes. The chapter will also explain how some participants developed health literacy but were not active in consultations or decision-making due to personal barriers or sometimes health professional barriers.

*Chapter 7-The development of health literacy in health education contexts*

This chapter explains how health literacy developed in the three health education contexts included in this thesis (self-management, structured diabetes-education and cardiac rehabilitation). The findings show that a range of health literacy skills can be developed and facilitated through both formal and informal learning opportunities, within the space and time of an education programme. How this happens and the processes involved will be explained in detail.

*Chapter 8-Discussion*

Chapter eight discusses the key findings of the thesis and sets the new and expanded health literacy categories within the context of the new Health Literacy Pathway Model and compares and contrasts it with some existing health literacy models. The strengths and limitations of the methods used will be discussed and the implications of the study findings will be discussed against a range of current issues that relate to health literacy. Finally, future research directions will be highlighted before the conclusion is presented.

## **2.0 Literature review**

### **2.1 Introduction**

This review of “health literacy” was undertaken in 2008 and focuses on four main topics: (1) definitions, conceptualisations and measurements of health literacy, (2) research evidence on health outcomes, (3) health literacy and patient involvement in healthcare processes and (4) educational strategies aimed at improving health literacy at individual or community levels. To conclude this review chapter, there will be a discussion of how definitions and measurements have shaped the research methods and thus what is currently known about health literacy.

### **2.2 The literature search**

#### **2.2.1 Search strategy**

The search was focused on identifying papers that (1) defined the concept of health literacy, developed measures of health literacy, or (2) examined the relationship of health literacy to patient health status, use of health care services, health knowledge and self-management behaviours, clinical outcomes, (3) patient involvement in healthcare (including decision-making), and (4) described educational strategies aimed at improving health literacy.

The following data bases were searched: MEDLINE, CINAHL, Embase, British Nursing Index, PsychInfo, Web of Science, Science Direct, Assia, The British Library Catalogue and SIGLE (for grey literature). The key words used were “health literacy” and “health and literacy”. Publications of leading researchers were hand searched and the reference lists of relevant articles were searched. Books that included health literacy in their title were also searched using the British Library catalogue and Google. The date-range of publications searched was from 1974 (the year that “health literacy” was first termed) to 2008. The total number of studies that came up in the search was 1,516.

### ***2.2.2 Initial appraisal of papers***

All titles and abstracts were screened for relevance and 378 abstracts were examined in more depth as particularly relevant. The number of papers read in full was 215, and 108 were kept for inclusion in the review. The criteria for including papers were those that were published in the English language and were about 'health literacy' and made assessments of health literacy using known measures of health literacy. Papers that measured 'literacy' were not included.

### ***2.2.3 Results***

The literature reviewed was broadly classified into four main areas of investigation that reflected the aims of the review: (1) definitions, conceptualisations and measurements of health literacy; (2) research evidence of health literacy outcomes; (3) health literacy and patient involvement; and (4) educational strategies aimed at improving health literacy. Although all papers focussed on health literacy, some refer to health literacy and literacy interchangeably and even refer to literacy when they have used health literacy measures to make assessments.

### ***2.2.4 A brief history of how health literacy research has developed since 1970***

The concept of health literacy originates from the United States and has partly evolved from an interest in the readability of health related materials by those in the field of health education and health promotion. The term 'health literacy' was first used in 1974 in a paper titled "Health Education as Social Policy" (Simonds 1974). The paper discussed health education as a social policy issue that affects the health-care system, the education system, and mass communication. Health literacy was presented as a goal for a minimum standard of health education for all school children in the US.

A review of early papers on health and literacy reported that there were approximately one dozen papers on literacy published in the medical and public health literature in the 1970s, two on barriers posed by health literacy, two on methods for assessing health education materials, and the remainder on the readability of health-related communications (Rudd 2007). Although there was little reference to the term health literacy between 1974 and 1992, by the middle of the 1980s there was an emerging field of research on low literacy and health information. A slightly broader scope of papers was identified in the 1980s literature, 37 in total. Seven papers were on general

issues of literacy, comprehension, and communication. A few papers related to tools for assessing reading materials, but most were reports on the assessment of written materials related to health and safety, informed consent, hospital discharge instructions, medicine, and patient education (Rudd et al. 1999). Some of the earliest research signifying a gap between health education materials and people's inability to understand them began after a landmark book was published in 1985 called *Teaching Patients with Low Literacy* (Doak et al. 1985).

In the 1990s there was growing interest in health and literacy, and according to Rudd et al. (1999), there were over one hundred publications in the first half of the decade alone. Some of the key papers instrumental to the development of relevant research at the time were on the relationship between literacy and health (Weiss et al. 1991; Weiss et al. 1992), the health status of illiterate adults (Weiss et al. 1992), and the relationship to illiteracy and healthcare costs (Weiss et al. 1994). In 1993 the results of the National Adult Literacy Survey (NALS) (Kirsch et al. 1993) identified that 90 million US adults (almost half of the US adult population) had problems with literacy (such as difficulty reading and inability to perform simple mathematical computations). At the same time health literacy measurement tools were being developed to help healthcare providers assess the health literacy of their patients.

During the second half of the 1990s most literature related to assessments of the reading level of health related materials. Definitions of health literacy were now emerging and health literacy tools, for example, the Test of Functional Health Literacy in Adults [TOFHLA] (Parker et al. 1995) and the Rapid Estimate of Adult Learning in Medicine [REALM] (Davis et al. 1993) were beginning to be used to investigate the relationship between health literacy and health outcomes. The findings of such research have offered insight into issues surrounding comprehension of basic medical instruction and explored how health literacy has an effect on chronic disease self-management, knowledge of screening and early detection of diseases (Rudd et al. 1999).



## **2.3 Part one – health literacy definitions, conceptual models and measurements**

### **2.3.1 Definitions of health literacy**

Early studies of health literacy used a definition of health literacy that focused on the ability to perform health related tasks that require reading and computational skills (Williams et al. 1995). For example, Parker et al. (1995) describe health literacy as:

**“...being able to apply literacy skills to health materials such as prescriptions, appointment cards, medicine labels, and directions for home health care”.**

**(Parker et al. 1995, p538)**

A similar skills-based approach to health literacy was proposed by the Ad Hoc Committee on Health Literacy for the Council of Scientific Affairs of the American Medical Association (1999):

**“....a constellation of skills, including the ability to perform basic reading and numerical skills required to function in the health care environment.”**

**(AMA, 1999, p553)**

The Institute of Medicine uses a definition of:

**“ The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”**

**(IOM, 2004. p32)**

This definition is widely cited in research and appears on most US policy documents pertaining to health literacy. It builds on earlier definitions to reflect the cognitive abilities to understand, analyse and apply health information in health related decision-making. However, there is no mention of any social skills that may be involved in the application of health literacy to decisions about health.

Nutbeam's (1998) definition of health literacy is used by the World Health Organisation (WHO) and is also widely cited in research:

**"Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health".**

**"Health literacy means more than transmitting information, developing skills to be able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment".**  
(Nutbeam 1998, p357)

Nutbeam's definition extends beyond a cognitive explanation and focuses also on social skills that are essential for interaction with others and society (e.g. skills in communication, negotiation and organisation). The focus on motivation in this definition of health literacy presents it as more of an action oriented concept rather than simply an intellectual capacity. Nutbeam (2000) views health literacy as an outcome of health education and health promotion which leads to both personal and social benefits for an individual.

Nutbeam's (2000) conceptualisation of health literacy is influenced by work on a typology of (general) literacy proposed by Freebody and Luke (1990) and their description of different types of literacy and how they can be applied in everyday life:

- ***Basic/functional literacy*** involves basic skills in reading and writing that enable a person to effectively function in everyday life
- ***Communicative/interactive literacy*** is a more advanced cognitive skill which combines with social skills and enables a person to gain meaning from their interactions
- ***Critical literacy*** is a more advanced cognitive and social skill that enables a person to critically analyse information and then use it to gain greater control over situations.

Freebody and Luke (1990)

Nutbeam's (2000) typology of health literacy features functional, communicative/interactive and critical health literacy and is described below:

- ***Functional health literacy*** - involves basic reading and writing skills that facilitate knowledge of health risks and use of healthcare services
- ***Interactive or communicative health literacy*** involves the social and personal skills and capacity that enable individuals to derive meaning from different forms of communication and to apply new information to changing circumstances
- ***Critical health literacy*** represents the cognitive and social skills that enable individuals to critically analyse information and also use it to support effective social and political action, in addition to individual action.

Nutbeam (2000)

Remaining consistent with Freebody and Luke's (1990) conceptualisation of literacy, each type involves more advanced skills which allow progressively more autonomy and empowerment for a person. Progression from one category to the next is dependent on cognitive development and exposure to different forms of communication and message content. A combination of cognitive skills in critical thinking, decision-making, problem solving and social skills in communication are needed to respond to these messages and in turn empower people to improve their own personal health and the health of their community (Nutbeam 2000).

Nutbeam's definition of health literacy places it as an important precondition for empowerment. Nutbeam proposes that there is a successive opportunity for autonomy and empowerment from functional health literacy to interactive health literacy through to the more advanced critical health literacy that is facilitated by an individual's cognitive and social development (Nutbeam 2000).

Kickbusch (2001) takes a similar empowerment approach to health literacy as Nutbeam (1998, 2000). Kickbusch and Maag (2008) describe health literacy as involving the development of skills that an individual needs to manage their own health and decision-making across a range of settings:

**“the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the marketplace and the political arena”.**  
(Kickbusch and Maag 2008, p 206)

Kickbusch and Maag’s model of health literacy takes into account patients’ abilities and skills to: access, process and use basic health knowledge, to adopt health promoting behaviours, to gain competence in navigating the health system, to communicate with health professionals, to select appropriate health services and to assume civic responsibility in exercising patient rights and advocacy. A significant feature of their definition is that it highlights the range of settings that health literacy is important in. Kwan et al’s (2006) definition of health literacy has similar qualities to this definition:

**“People’s ability to find, understand, appraise and communicate information to engage with the demands of different health contexts to promote health across the life-course”.**  
Kwan et al. (2006)

In addition to highlighting the range of abilities and the inclusion of different health contexts that relate to health literacy, this definition draws attention to the need for health literacy throughout one’s lifetime.

Zarcadoolas et al. (2003) extend the more functional descriptions of health literacy and also Nutbeam’s (2000) typology:

**“the wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life.”**  
(Zarcadoolas et al. 2003, p119)

Their model of health literacy is based on the four dimensions (categories) described below:

- **Fundamental literacy:** basic skills of literacy, language and numeracy (similar to functional health literacy).
- **Scientific literacy:** understanding the science behind health and health improvement.
- **Cultural literacy:** understanding how health literacy can be influenced by culture, in terms of how information is received, delivered and internalised.
- **Civic literacy:** understanding of what it means to be a citizen and how this relates to health. Examples of civic health literacy are the uptake of immunisation and health protection.

Zarcadoolas et al. (2003, 2006)

In this model a skill in one domain can support the development of a skill in another health literacy domain, and at times even compensate for a lack of competence in another literacy skill. Health literacy is characterised as a continuous variable that evolves over a person's lifetime and is influenced by health status in addition to demographic, socio-political, psychosocial and cultural factors. Zarcadoolas et al. (2006) argue that health literacy consists of a dynamic set of productive and generative skills that a person can use when facing new situations. It is this generative nature of health literacy that enables people to apply existing skills and knowledge to novel situations and facilitates informed decisions, healthier choices, and a degree of autonomy.

### *Dual approaches to health literacy*

Pleasant and Kuruvilla (2008) suggest there are two approaches to health literacy: a clinical approach and a public health approach. The clinical approach characterises health literacy as an individual level problem and focuses on patients' communication with physicians and their understandings of treatment regimens. The clinical approach is more prominent in the United States, where there is a strong focus on functional health literacy. The public health approach is more prominent in Europe, focused on health promotion and public health interventions. Health literacy is viewed as both an

individual characteristic and also a key determinant of population health (Kickbush 2001).

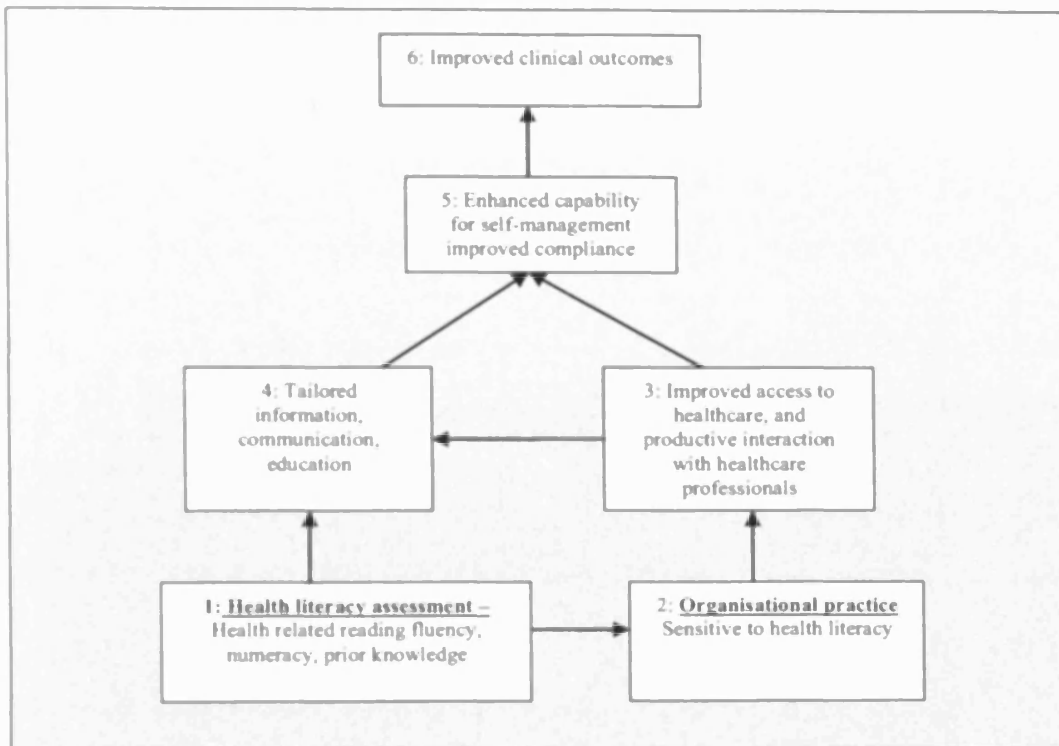
The main differences between the US and the European approaches are that the latter incorporates the essence of empowerment. Nutbeam (1998, 2000) and Kickbusch (2001) make references to empowerment and draw on elements of critical social theory to conceptualise health literacy and health education. Both have been inspired by Paulo Freire's (1985) approach to adult learning as enabling liberation from oppression. Freire (1970, 1985) believed that the economic, political and social relations that are often exemplified in vulnerable populations are reflected in educational experiences that maintain powerlessness by treating learners as passive subjects. Applying Freire's empowerment approach to health education represents patients as potentially active agents in their learning. Nutbeam's 'critical health literacy' is reflective of Freire's 'critical consciousnesses' (Freire 1970).

### *2.3.2 Recent conceptual developments in health literacy*

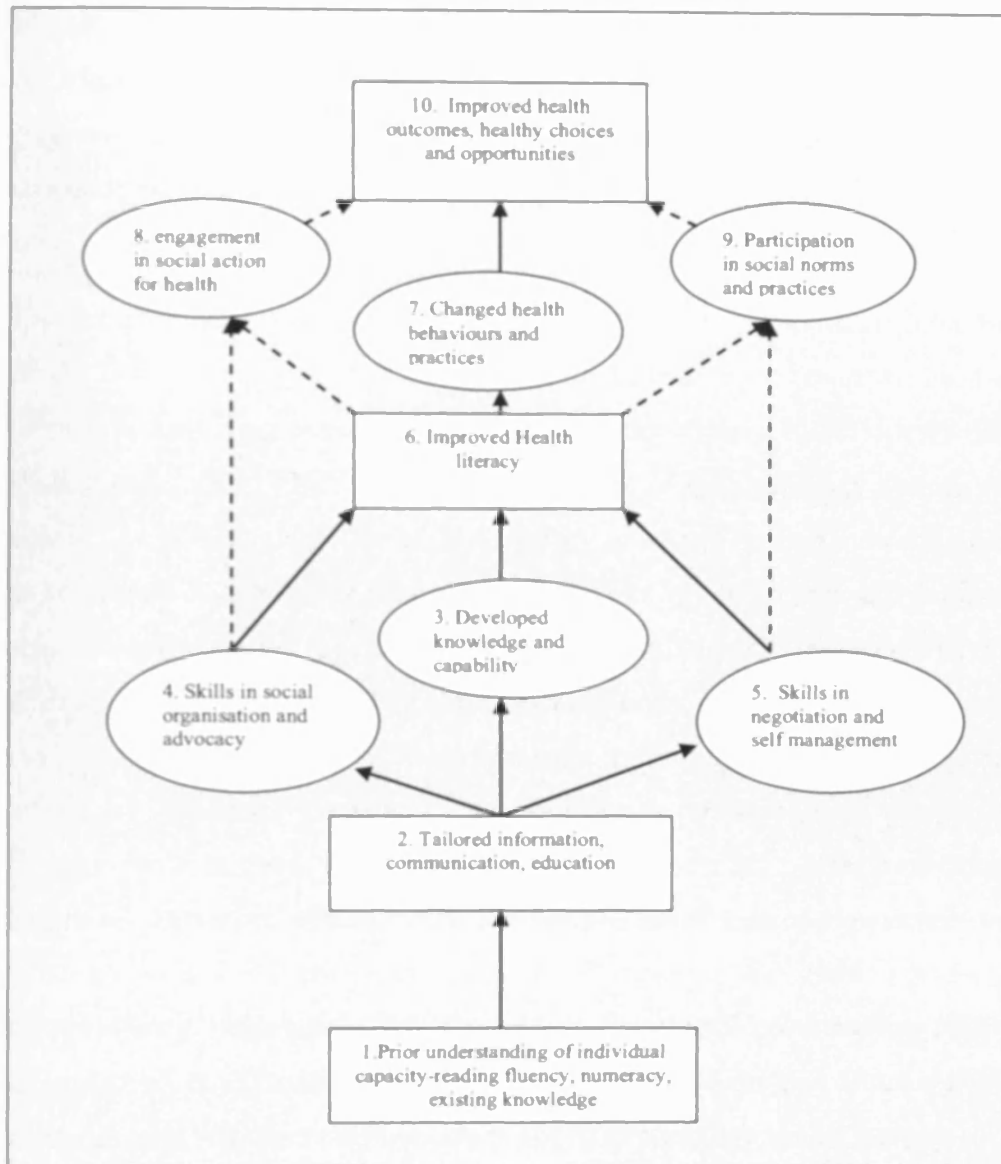
Nutbeam (2009) has put forward two further differing conceptualisations of health literacy to describe how it impacts on health outcomes. One views health literacy as a risk factor or deficit that can be identified and managed in clinical care (by assessment) and another conceptualisation views health literacy as a personal asset.

#### *Health literacy as a risk*

The risk model (see figure 2.1 below) emphasises the importance of communication and health service organisation that is tailored to the needs of low literate individuals. It proposes that tailored health information and education, provided to patients by a clinician are likely to result in improved capabilities to adhere to clinical recommendations. These in turn are understood to lead to appropriate and successful care plans and improved health outcomes. The risk approach is similar to the clinical approach (Pleasant and Kuruvilla 2008) and underpins much of the research that has been carried out on health literacy and health outcomes.

**Figure 2.1 Health literacy as a risk model (Nutbeam 2009)***Health literacy as an asset*

Nutbeam's (2009) "health literacy as an asset" approach has evolved from public health and health promotion (see figure 2.2 below). It is representative of a public health and empowerment approach to health literacy (Pleasant and Kuruvilla 2008). Health literacy is described as an asset to be developed, and is also seen as an outcome of health education and communication.

**Figure 2.2 Health literacy as an asset (Nutbeam 2009)**

Here Nutbeam accounts for individuals' prior knowledge and capability and the importance of tailored information, communication and education. Health literacy is featured as an outcome of education and communication. Health literate individuals are thus equipped with skills and capabilities that enable them to engage in a number of individual and social actions and personal health behaviours that enhance their health and influence the health behaviour of others. The ultimate outcomes of this model are the capacity for improved health outcomes, opportunities to enhance health and the ability to make health choices.



Nutbeam (2009) claims that the asset model can be applied to a wide range of health education settings and can extend from the clinical setting into the community. For example it can be applied to schools, adult learning and community health projects. However, the model is yet to be empirically tested and more research is needed to provide an evidence base.

### *2.3.3 Conceptual analyses of health literacy*

There are two conceptual analysis papers in the literature (Mancuso 2008; Speros 2005). Both have reviewed the health literacy literature and conceptualised health literacy as furthering nursing research and practice. Speros (2005) used a method by Walker and Avant (1995) to analyse the concept of health literacy with an aim to clarify its meaning and promotes consistency in using the term in nursing dialogue and research. A number of attributes, antecedents, consequences and empirical referents associated with health literacy are identified based on research evidence. The defining attributes are: reading and numeracy skills, comprehension, the capacity to use health information in healthcare decision-making, and successful functioning as a healthcare consumer. The antecedents are: literacy (ability to read, comprehend written words, numeracy), and health related experiences (e.g. exposure to medical language). However, although both literacy and health related experiences contribute to health literacy, it is not clear to what extent these are important to developing health literacy. It is entirely feasible that a person with a lower reading ability, comprehension and numeracy but who has years of experience of managing a health condition and healthcare encounters might have adequate health literacy.

Speros (2005) explains the consequences of health literacy as improved self-reported health status, lower healthcare costs, increased knowledge, shorter hospital stays, and less frequent use of healthcare services. Empirical referents to health literacy are identified as the Test of Functional Health Literacy in Adults (TOFHLA) and the component of the National Assessment of Adult Literacy (NAAL), developed by the US Department of Education. However, the concept of health literacy is relatively new and evolving and these referents can be subject to change. Furthermore, the TOFHLA has been criticised as functioning as more of a reading comprehension test than a measure of health literacy, and the NAALS is a US-centric measure of some aspects of health literacy. Although this conceptual analysis is useful to help nurses

recognise patients with health literacy problems and to assess the potential risks involved with inadequate health literacy, it does relatively little to advance the concept and fails to consider the full extent of the ambiguities associated with multiple definitions of health literacy and problems associated with measuring the concept.

Mancuso (2008) used a method by Rodgers (2000) to identify attributes, antecedents and consequences of health literacy and produce a new definition of health literacy (see figure 2.3 below). A wider range of antecedents to health literacy are proposed that reflect a number of ways that health literacy has been described in the literature. These forms of *competence* are as follows:

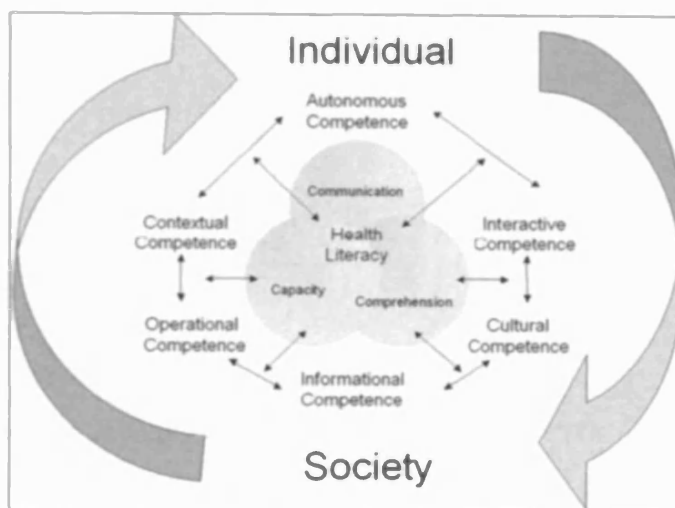
- Operational – reflective of the ability to read, understand and act on written and oral information.
- Interactive – collaboration with others (e.g. health professionals) to assist in self-management of one's health and the ability to derive meaning from forms of communication.
- Autonomous – reflective of personal empowerment and self-awareness needed to assume responsibility for health decisions and the ability to evaluate and use information and relate it to take actions involving one's own health.
- Informational – the ability to recognise a need for information and use strategies to seek and effectively use appropriate sources in order to make health decisions.
- Contextual – this form of competence involves mastery of the healthcare environment (e.g. finding way around hospitals).
- Cultural – reflective of recognising and using collective beliefs, customs and social identity to make sense of and act on health beliefs.

The attributes in this model are enmeshed within these antecedents and demonstrate the more basic and inherent characteristics of health literacy:

- Capacity – partly innate potential and partly learned skills including obtaining, analysing and evaluating health information, oral language skills, social skills and the typical reading, numerical, listening, analytical and decision-making skills that are needed to act on information.

- Comprehension – the logic, language and experience required to understand the meaning of information. This attribute is important to critical-thinking and problem-solving.
- Communication – the exchange of information and skills in active listening, critical observation, insightful reading and expressing information to others in a way that can be understood.

**Figure 2.3 A conceptual model of health literacy (Mancuso 2008)**



The consequences of inadequate health literacy in this model are similar to Speros' (2005) model. These are summarised as: increased healthcare costs, less knowledge of disease, fewer self-management skills and ability to care for chronic conditions, poor compliance, greater risk of hospitalisation and even a greater risk of disease and disability. The definition of health literacy proposed from this analysis is:

**"a process that evolves over one's lifetime and encompasses the attributes of capacity, comprehension and communication".**  
(Mancuso 2008, p252)

The above definition is unique in that it highlights health literacy as a *process*. Whereas other models represent the concept as a *capacity* (e.g. IOM 2004) or an *outcome* (e.g. Nutbeam 2000). It may be likely that health literacy is all three (i.e. a

capacity, a process and an outcome). Further research is needed to explore the utility of health literacy within these three frames of reference.

Both Speros' and Mancuso's conceptual ideas can guide research efforts on the more salient antecedents of health literacy. However, it is important to note that the research evidence on which both Speros' and Mancuso's analyses are based has drawn conclusions about proposed outcomes of health literacy by making use of a number of different definitions and problematic health literacy measures. In order to propose a more comprehensive conceptual analysis of health literacy it is necessary to review these measurements and how they have been used to provide evidence of health literacy outcomes.

#### *2.3.4 Measuring health literacy*

The first health literacy assessment to be developed was the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al. 1993). The REALM was designed to be used in primary care and public health settings to identify patients with low reading levels. It consists of a list of words and the patient has to verbalise each word. Essentially, it is a measure of word recognition and reading ability. The maximum score is 66 and the raw scores are converted into reading levels based on four different levels of US high school achievement. Scores 0-18 are equal to third grade or below (may not be able to read most low literacy materials, may need repeated oral instructions, materials composed primarily of illustrations, or audio or video tapes). Scores 19-44 are equal to fourth to sixth grade (may need low-literacy materials, may not be able to read prescription labels). Scores 45-60 are equivalent to seventh to eighth grade (may struggle with most currently available patient education materials). Scores 61-66 are equivalent to ninth grade and above (should be able to read most patient education materials).

The Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al. 1995) was designed to measure functional health literacy in clinical practice and has since been used in research. The test includes 17 items on numeracy and 50 items on literacy. In order to measure comprehension and the ability to read and understand prose passages, it uses a procedure where each passage has every fifth to seventh word deleted and the respondent must select from a list of four words the one that best fits

the sentence (a method known as the Cloze procedure). The maximum score is 100 and participants are classified into one of three health literacy categories, depending on their score. These are: *inadequate health literacy* (unable to read and interpret healthcare related texts; scores between 0-59); *marginal health literacy* (has difficulty reading and interpreting healthcare texts; scores between 60-74), and *adequate health literacy* (can read and interpret most health care texts; scores between 75-100).

Both the REALM and the TOFHLA are the most frequently used tools in research to investigate the relationship between the complexities of health information and the health literacy abilities of people. However, patients' levels of literacy are usually referred to in research as *inadequate, marginal, or adequate*.

The Newest Vital Sign (NVS) (Weiss et al. 2005) is a 6-item literacy assessment structured around the activity of reading and demonstrating an understanding of information included in on a nutrition label. The NVS was developed to screen for limited literacy in primary health care settings. It is administered by interview and the interviewer asks six questions relating to how the patient would interpret and act on information contained in a nutritional label from an ice cream container. One point is given for each correct answer and scores are categorised as a high likelihood of marginal/inadequate literacy, possibility of marginal/inadequate literacy, and adequate literacy. In comparison to the REALM and a short version of the TOFHLA (S-TOFHLA, Baker et al. 1999) (see below), the NVS has a high sensitivity to detecting limited literacy. However, the tool was less sensitive in classifying adequate literacy against the other two measures. Scores on the NVS have also been found not to be associated with health knowledge and outcomes and is not a good tool for research purposes compared to the REALM and the S-TOFHLA (Osborn et al. 2007).

#### *Short versions of health literacy measures*

Health literacy measures have been shortened for quicker use in practice. For example, a shorter version, S-TOFHLA was later developed to include four numeracy items and two prose passages (Baker et al. 1999). This measure is frequently used in research. A shorter version of the REALM (REALM-R) has also been developed (Bass et al. 2003). However, it has only been tested on a sample of 157 patients in one study and needs more empirical testing.

Further efforts to reduce the time it takes to assess health literacy and identify patients with inadequate health literacy have involved the development of three brief screening questions (Chew et al. 2004):

- How often do you have someone help you read hospital materials?
- How confident are you filling out medical forms by yourself?
- How often do you have problems learning about your medical condition because of difficulty understanding written information?

The effectiveness of this 3-item screening test has been evaluated in further studies and found to be useful for clinical practice (Wallace et al. 2006; 2007). However, one single question was the most effective and was suggested to be sufficient for detecting limited and marginal health literacy:

**“How confident are you filling out medical forms by yourself?”**

Another Single Item Literacy Screener (SILS) (Morris et al. 2006) asks:

**“How often do you need to have someone help you when you read instructions, pamphlets, or written material from your doctor or pharmacy?”**

The SILS was found to be moderately effective in identifying those of limited reading ability. However, the measure is not a full measure of health literacy as reading ability is just one component of health literacy. Both the three item health literacy screening test (Chew et al. 2004) and a single-item test (Morris et al. 2006a) may be suitable in clinical practice, allowing health professionals to gauge the literacy levels of their patients and tailor their communication and patient education efforts. However, they are better measures of literacy applied to health information, rather than comprehensive estimates of health literacy. Therefore, they are not widely used in research on health outcomes.

To date most health literacy assessments give more of an indication of patients' reading level. They cannot be used to explain the complex range of skills needed for health literacy as it now described. For example, Nutbeam (2000) suggests that

adequate health literacy assessed by the ability to read and write does not guarantee a person will respond to health education and communication strategies. The Institute of Medicine in the US recommends that more aspects of health literacy such as verbal health communication skills, cultural and conceptual knowledge, understanding of risks to health, and preventative health behaviours should be taken into account in a measurement of health literacy (Nielsen-Bohlman et al. 2004).

#### *Expanded versions of health literacy measures*

The Health Activities Literacy Scale (HALS) (developed in the US by the Educational Testing Service) has been specifically designed to assess activities that are not necessarily confined to traditional healthcare settings such as doctors' surgeries, hospitals and clinics, but those that take place in the home, at work or in the community.

The HALS has been compiled from questions from the NALS and tests prose, quantitative and document measures activities associated with the following:

- Health promotion (activities that enhance and maintain health)
- Health protection (understanding materials produced to attempt to safeguard health)
- Disease prevention (behaviours taken to prevent illness/detect disease)
- Health care and maintenance (activities to learn more about an illness or follow a prescribed regimen)
- System navigation (ability to read/understand bureaucratic and regulatory information *i.e. rights and responsibilities, informed consent*).

One disadvantage of HALS for use in research studies is that it is time consuming and answering 191 questions in the full length version can take up to one hour. Even the "locator" version takes 30-40 minutes. Even though the HALS is a more comprehensive test of health literacy both versions are considerably longer than the REALM and the S-TOFHLA. Furthermore, it is not yet known whether increasing the comprehensiveness and length of tests will translate to greater predictive value and discriminatory ability.

A group of researchers from Japan (Ishikawa et al. 2008a; Ishikawa et al. 2008b) has developed a health literacy instrument to measure functional, communicative and critical health literacy based on Nutbeam's typology (Nutbeam 2000). However, the instrument is in the form of a self-report questionnaire and may be limited because of the shame and embarrassment associated with poor reading ability (Parikh et al. 1996a). Thus, the use of a self-report measure of health literacy may lead to an over-estimation of health literacy in a research population and in clinical practice. The scale is in its early stage of development and has so far only been used in a Japanese sample. Furthermore, it has not been compared to other health literacy measures used in research. Thus, the scale needs to be refined and validated for measuring communicative and critical health literacy and adapted for use in an English-speaking population.

#### *2.3.5 Section summary*

Definitions of health literacy have been extended from a set of reading and numeracy based skills (Baker et al. 1999; Parker et al. 1995) to consider a range of cognitive and social skills that help people relate to health information and make health-related decisions across a range of settings (Kickbusch 2001; Nutbeam 2000). Health literacy has evolved into a concept that surpasses functional literacy abilities. Recent conceptual developments have incorporated the understanding of health communication, critical analysis of information, using information for oneself or the benefit of the community (Nutbeam 2000); and understanding scientific aspects of health, cultural understanding of health and civic responsibilities involved in health actions (Zarcadoolas et al. 2005, 2006).

This section has shown how health literacy has been studied from differing perspectives. There is a clinical perspective (Pleasant and Kuruvilla 2008) and a risk perspective (Nutbeam 2008) where health literacy is seen as an individual problem that needs to be managed in order to achieve compliance with medical instructions. There is also a public health perspective that is focused around health promotion and empowerment (Nutbeam 2008), and an asset approach where health literacy can be developed through tailored information, communication and education. Conceptual analyses of health literacy from the field of nursing (Mancuso 2008; Speros 2005) have identified a number of antecedents, attributes and consequences of health



literacy. Such analyses may be useful in helping health care professionals understand and identify health literacy issues in practice.

Current health literacy measures reflect skill-based definitions of health literacy. Shorter measures have been developed for quicker assessment in clinical practice, but still only reflect reading ability and reading comprehension. Whilst the HALS is a more comprehensive measure it is too time consuming for use in clinical practice and health outcome research. A Japanese self-report health literacy scale (Ishikawa et al. 2008b) based on Nutbeam's (2000) typology is also more comprehensive but needs translation to English and further testing before it can be validated as a measure.

## ***2.4 Part two - The empirical research evidence***

Health literacy assessments have been used in numerous cross-sectional studies to estimate the prevalence of low health literacy in society and its relationship with various outcomes (such as health status, disease knowledge, health service use and doctor patient communication). This section will review the evidence from such research. Although there is variation between and within studies on whether the concept being measured is termed literacy or health literacy, the research evidence presented will include studies that have used either the REALM or the TOFHLA.

### ***2.4.1 Prevalence***

The first ever investigation of the prevalence of health literacy was in a large sample of patients (2,659) presenting for acute care in two urban public hospitals in the United States (Williams et al. 1995). Thirty-five percent of English speaking participants and 61% of Spanish speaking patients had inadequate or marginal health literacy. The results were significantly higher (over 80%) where patients were older than 60 years of age (Williams et al. 1995). A systematic review of 85 studies including a sample of 31,129 participants in the United States reported that over 25% of all participants had "inadequate" health literacy and another 20% had "marginal" health literacy (Paasche-Orlow et al. 2005). This may also have lead to an over-representation of people with lower educational attainment and lower literacy skills. Thus, health literacy prevalence in the general population is not usually taken into account in prevalence studies. In the UK, inadequate and marginal health literacy rates have been suggested to be much lower. For example, Von Wagner *et al.*, (2007)

reported an estimated prevalence of 10% for limited health literacy (5.7% inadequate health literacy and 5.7% marginal health literacy). This estimate was based on a general (non-clinical cohort) sample of UK 759 patients. At present, a UK population-based health literacy survey is in development. Once it has been put to use there will be a better estimate of the prevalence of inadequate and marginal health literacy.

One criticism of estimating the prevalence of health literacy through combining the research evidence of studies of health literacy is that most studies have used clinical cohorts, which tend to include an over-representation of people from more socially disadvantaged backgrounds (Von Wagner et al. (2007). Thus, they do not provide evidence of health literacy in the general population. Furthermore, estimating the prevalence of health literacy using research evidence is even further complicated by the use of differing measures of health literacy, which do not represent the construct of “health literacy” in the same way and have different interpretations of inadequate, marginal and adequate health literacy (see section 2.34, page 35).

#### *2.4.2 Health outcomes -Health literacy and knowledge of chronic condition*

Based on the premise that health literacy may affect a patient’s ability to acquire sufficient knowledge, tests of knowledge or comprehension of health information are commonly used as an intermediate outcome measure in health literacy research (DeWalt and Pignone 2005). In one study, inadequate and marginal health literacy was associated with less knowledge of four chronic illness conditions (diabetes, asthma, coronary heart failure and hypertension) (Gazmararian et al. 2003). Health literacy level was a predictor of patients’ knowledge even after controlling for age, disease duration and prior attendance at a disease-specific education class.

#### *Asthma Knowledge*

Lower health literacy has been related to lower asthma knowledge scores (Mancuso and Rincon 2006; Williams et al. 1998a) and poor asthma self- management skills (Williams et al. 1998a). Patients with lower health literacy were less likely to consider the potential harm of asthma episodes, know about monitoring lung function, and know about warning signs (Mancuso and Rincon 2006).

### *Diabetes Knowledge*

Williams et al. (1998b) found a relationship between inadequate health literacy and less knowledge of diabetes and hypertension. Most of the patients (73%) had attended diabetes education classes. However, there was no significant relationship between functional health literacy scores and the number of diabetes classes attended. The researchers suggest that despite attending classes patients with inadequate health literacy had less knowledge of their disease and that patient education strategies may not reach patients with poor health literacy. However, there was no relationship between functional health literacy and diabetes outcomes (blood glucose level) and/or hypertension (blood pressure measurements). Powell et al., (2007) found that even though limited health literacy was significantly associated with both poorer knowledge of diabetes and worse glycemic control, it was not significantly correlated to readiness to take action in diabetes management (as measured by the Diabetes Health Belief Model Scale, Harris et al. 1987).

Kim et al., (2004) examined the relationship of health literacy with self-management behaviours in patients with diabetes following diabetes education. Poorer health literacy was associated with more self-reported diabetes complications. However, health literacy was not associated with HbA1c or self management behaviours. Patients with adequate health literacy had higher knowledge scores. However, there were no significant differences in glycemic control between adequate health literacy and limited health literacy groups. Patients with limited health literacy reported better adherence to diet, self-glucose monitoring and foot care (as assessed by the Summary of Diabetes Self-Care Activities measure, a valid self-report measure that assesses how often self-care activities are performed in a given week).

### *HIV knowledge*

Limited health literacy in HIV patients has been associated with less knowledge of two common markers for tracking the progression of HIV infection (CD4 counts and viral loads) and understanding what these two markers mean. Patients with lower health literacy also had more misperceptions about treatment and were more likely to visit their doctor on a monthly basis (Kalichman et al. 2000). Low health literacy has also been associated with poor knowledge of medication, incorrectly taking medication, and not understanding the meaning of CD4 count or viral load (Wolf et

al. 2004). However, this study had a high representation of patients with limited health literacy (48 percent), a high number of Black participants (59 percent), and less than high school education (37 percent). Both these HIV studies used convenience samples drawn from the community. Accordingly, generalising their results to other populations of HIV patients should be treated with caution.

#### *Screening knowledge and use of screening services*

Inadequate health literacy has been associated with lower knowledge and understanding of various screening tests such as prenatal screening (Cho et al. 2007), Papanicolaou (Pap) smears (Lindau et al. 2002), mammography (Davis et al. 1996) and colorectal cancer screening (Miller et al. 2007; Peterson et al. 2007). However, some of the evidence of the association between health literacy and screening tests does not support an association between health literacy and screening behaviour. In both studies of colorectal cancer screening there was no significant association between inadequate health literacy and screening rates (Miller et al. 2007; Peterson et al. 2007).

In one study of follow up screening after an abnormal pap smear, health literacy as measured by the REALM was not significantly associated with likeliness to attend a follow up appointment (Lindau et al. 2006). However, a subjective estimate of low literacy (patient's level of reading ability) given by a physician was associated with failure to present at follow up appointments. The results reflect the current issues with the appropriateness of current health literacy measures such as the REALM and the TOFHLA. Because the REALM is essentially a reading test the physician's estimate of reading ability level may be comparable. Nevertheless, both assessments do not measure of the concept of health literacy as it is now more widely defined.

#### *Medication knowledge and adherence*

Two studies of patients taking warfarin show conflicting results regarding the influence of health literacy. One study of patients taking warfarin reported that low health literacy and low numeracy were significantly associated with poorer anticoagulation control (as indicated by international normalisation ratio (INR) variability) (Estrada et al. 2004). The results indicate that those with lower health literacy may be poor at adhering to warfarin or managing their condition. A more

recent study of patients taking warfarin found that patients with limited health literacy had a lower knowledge of the medication, had poorer knowledge of atrial fibrillation and were less aware of their increased risk of stroke. However, there was no association with warfarin adherence or INR control (Fang et al. 2006). These findings compare with other studies of patients with a chronic condition where those with limited health literacy scored low on tests of knowledge of their condition but had outcome indicators that suggest they may be managing their condition well (Kim et al. 2004; Williams et al. 1998b).

#### *2.4.3 Health literacy and clinical outcome measures*

Schillinger et al., (2002) reported that inadequate health literacy is independently associated with measures of poor glycaemic control and higher rates of retinopathy. A systematic literature review of studies of the relationship between health literacy and health outcomes has reported that those who have lower health literacy are 1.5-3 times more likely to have an adverse health outcome than those with better health literacy (Dewalt et al. 2004). However, since this review the evidence has been more mixed, and not all studies have supported a relationship between health literacy and clinical outcomes (Kim et al. 2004; Williams et al. 1998b). In addition, a study of 1,002 adults with diabetes also reported no significant relationship between health literacy and health outcomes for glycemic control, blood pressure, or dyslipidemia in diabetic adults (Morris et al. 2006b).

Ishikawa et al., (2008c) found no association between HbA1C levels and functional health literacy, but an association was present between higher communicative (or interactive) health literacy and lower HbA1C levels. This may mean that communicative (or interactive) health literacy skills such as retrieving, communicating and applying information may be particularly important in managing diabetes, and may also be more important than skills needed to read information (i.e. functional health literacy skills). However, lower functional health literacy was associated with higher rates of diabetes complications, which suggests that there may be some self-management issues that are connected to lower functional health literacy. The authors conclude that health literacy may be directly associated with clinical outcomes for diabetes, but each health literacy level might act in a different way. Ishikawa's study indicates that there may not be a linear relationship between

Nutbeam's three types of health literacy and that people may draw on skills from each level depending on the tasks needed to manage their health.

#### *2.4.4 Health status, mortality and healthcare service utilisation*

Baker et al (1997) reported that patients with inadequate functional health literacy were more likely to report poor health than those with adequate functional health literacy. In another study of patients with diabetes the prevalence of limited health literacy was almost twice as high in patients who had self-reported heart failure symptoms as those who had not. However, the relationship was only significant in patients who had both lower health literacy and fewer years in education.

A longitudinal study of asthma patients found health literacy to be associated with worse asthma-related quality of life, worse physical function and more emergency department use over two years when compared to patients with higher health literacy (Mancuso and Rincon 2006).

One longitudinal study reported that over the period from 1994-1995, patients with inadequate functional health literacy were twice as likely to have been hospitalised compared to patients with adequate functional health literacy (Baker et al. 1998). A later study of health literacy and hospital admission rates in a large cohort (N=3260) of elderly managed care enrollees (Baker et al. 2002) found that inadequate functional health literacy was an independent risk factor for hospital admission.

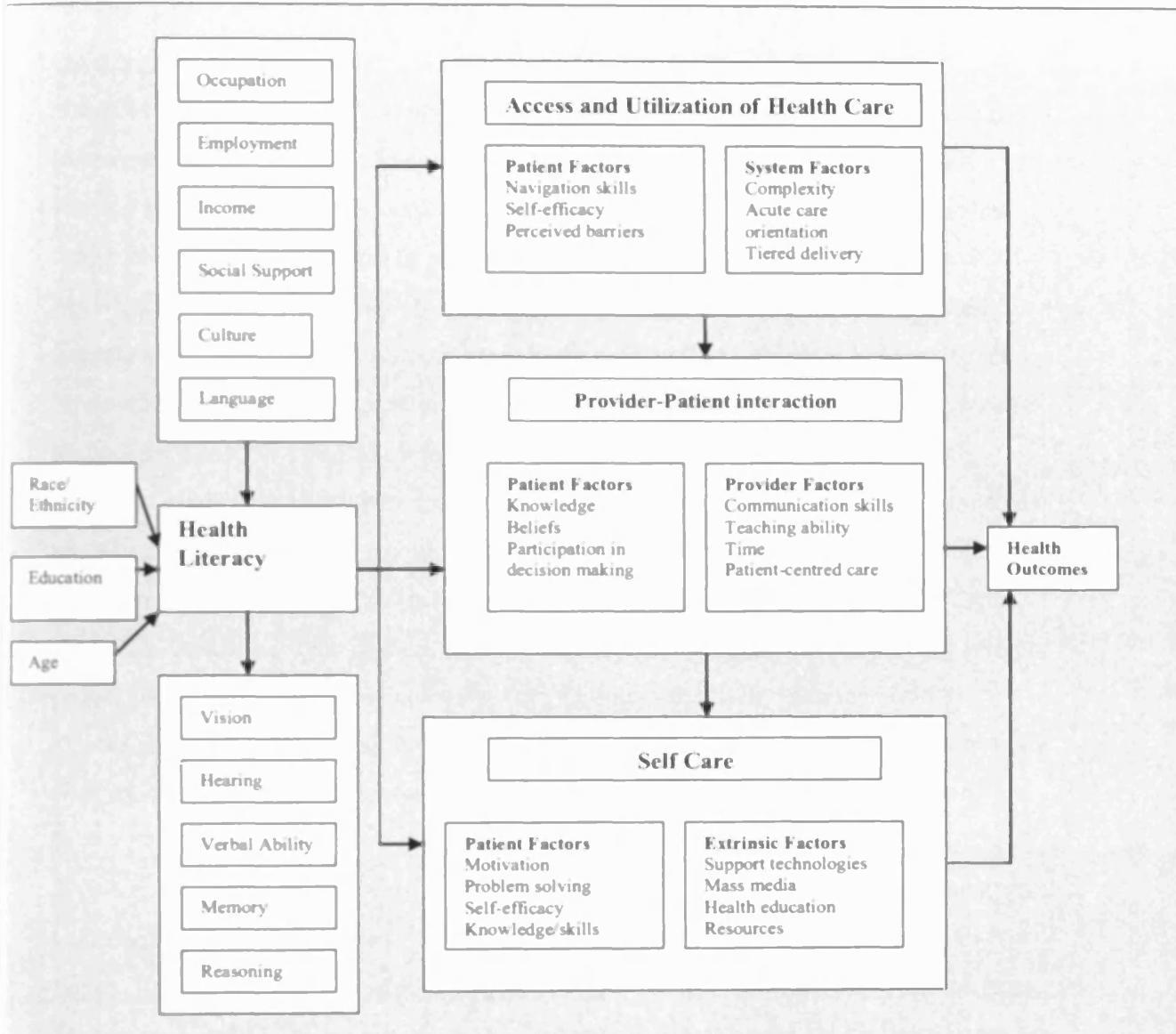
More recently Wolf et al., (2010) found a continuous graded relationship between literacy and baseline physical functioning. They offered two possible explanations. Firstly, the measure they used (S-TOFHLA) could capture the variance in health outcomes that have been explained by socioeconomic status (which has also been found to have a graded relationship with health outcomes) and other variables that mediate the relationship (e.g. poor nutrition, psychological stress, and poor access to quality healthcare). Secondly, Wolf et al., (2010) suggest that literacy may be causally associated with physical functioning. For example, decreases in cognitive skills may progressively lead to less understanding of how to stay healthy, when to seek healthcare and how to follow medication regimes in order to recover from illness or care for a long-term condition. However, in their examination of mental health there was a threshold where participants scoring below the third literacy category had

significantly worse mental health than those in the highest category. Health literacy was associated with greater all-cause mortality risk; again there was a threshold below the third category which was significantly associated with increased mortality. The authors conclude that the nature of the relationship between literacy and health may vary depending upon the outcomes that are being measured.

#### *2.4.5 Causal pathways from health literacy to health outcomes*

Because most research on health literacy and outcomes has been cross-sectional in design, the nature and complexities of causal pathways linking health literacy and health is less understood. Paasche-Orlow and Wolf (2007a) conducted an evidence-based review of the health literacy outcome research and developed a conceptual model that seeks to explain the causal pathways linking health literacy to health outcomes (see figure 2.4 below). The model presents health literacy as both a patient and health system phenomenon and incorporates the abilities of the patient and the complexity of the tasks at hand. The model (figure 2.4) includes individual and system level factors that influence access and utilization of healthcare, patient-provider interaction, and self-care activities.

**Figure 2.4 Causal Pathways between limited health literacy and health outcomes**  
(Paasche-Orlow and Wolf 2007a)



There are limitations with the model that stem from problems associated with the way health literacy has been defined and measured and the research design of outcome studies. For example, health literacy is presented as a fixed and dichotomous characteristic and the model does not account for different dimensions of health literacy (e.g. Nutbeam 2000; Zarcadoolas et al. 2005) and the way health literacy may evolve over time. The model portrays the links between health literacy and health outcomes in a linear fashion. However, the relationships between the variables in the model may be more complex and dynamic than presented. The authors acknowledge that more longitudinal empirical research is needed to help explain the complex nature



of the relationships between causal variables and their influences on health literacy and health outcomes.

#### *2.4.6 Section Summary*

Current health literacy measures (e.g. the TOFHLA and the REALM) have been used to estimate the prevalence of health literacy and the relationship between health literacy and various health outcome variables. Patients with inadequate or marginal health literacy generally tend to perform poorly on written and verbal tests of knowledge of their condition. However, the evidence of the effect of a combined limitation in knowledge and health literacy on measurable outcomes is more mixed. Some studies show a relationship between inadequate health literacy, less knowledge and poorer health status and clinical outcome measures (Kalichman et al. 2000; Williams et al. 1998a). However, in other studies patients' health behaviours (such as attending screening) (Miller et al. 2007; Peterson et al. 2007), self-management outcome measures (e.g. blood pressure, glucose levels) (Kim et al. 2004; Williams et al. 1998b) and adherence to medication or diet are not always poor and do not reflect problems with knowledge or health literacy (Fang et al. 2006; Kim et al. 2004). One explanation may be that those with poorer health literacy may be more compliant with medical instruction and may not engage with, or retain, health information.

A review of studies of the relationship between health literacy and clinical outcomes has reported patients with low literacy are 1.5 to 3 times more likely to have adverse health outcomes. However, the evidence since the review has been more mixed (e.g. Morris et al. 2006). There is even some evidence that functional health literacy has no effect on diabetic outcomes but interactive health literacy (Nutbeam 2000) may have a positive effect on outcomes (Ishikawa et al. 2008b).

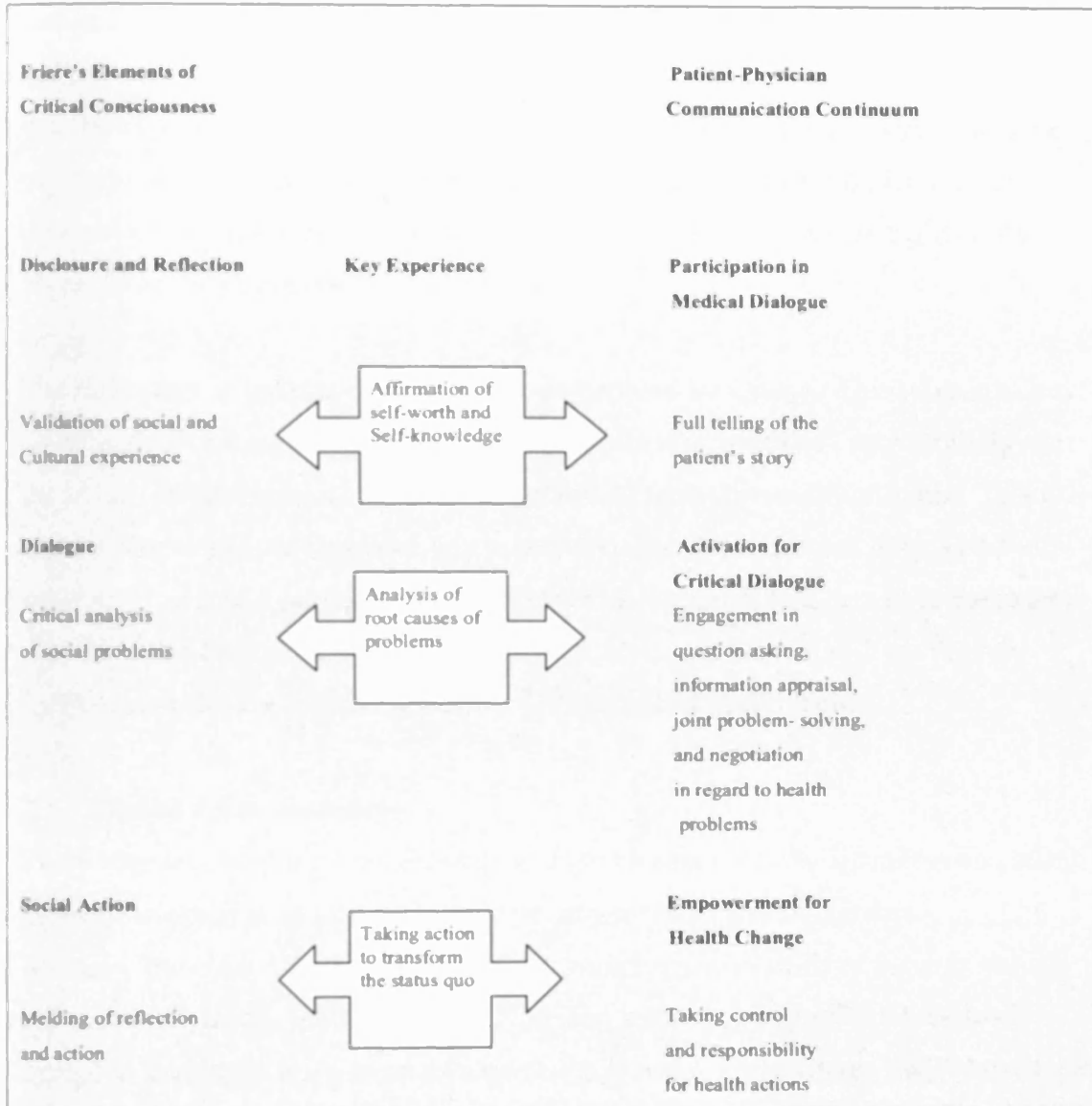
## **2.5 Part Three – Health literacy and patient involvement in healthcare processes**

### **2.5.1 Patient-provider interaction**

A review of studies investigating the impact of health literacy on patient-physician communication has indicated that insufficient comprehension of vocabulary, limited health knowledge, and impaired ability to assimilate new information and concepts play a role in the ability of patients with health literacy problems to communicate with healthcare providers (Williams et al. 2002). Some patients with inadequate health literacy have problems understanding medication instructions or the significance of their diagnosis (e.g. Williams et al. 1998b). A study of health literacy and patient-physician communication in diabetic patients (Schillinger et al. 2004) reported that those with inadequate health literacy had worse communication skills related to understanding physicians' explanations of their condition and explanations of processes of care. Schillinger et al (2004) suggest that those with inadequate health literacy are likely to be less informed about their condition and the process of care needed to successfully manage it. Patients with inadequate health literacy have been reported to be more likely to feel overwhelmed by information and tend to ask fewer questions in consultations (Artinian et al. 2001). The shame associated with low literacy also exacerbates communication problems (Parikh et al. 1996).

Roter (2005) has produced a useful conceptualisation of patient-physician communication using Freire's (1983) elements of critical consciousness and explains how low health literacy can affect each stage in the model (see figure 2.5 below). Freire's (1983) theory places adult learners as active agents in their own learning, leading to educational experiences that facilitate the competence and confidence needed to make a personal transformation and realise a "critical consciousness". Three key adult education experiences are suggested to influence such a transformation. These are: relating and reflecting on experience, engaging in critical dialogue, and taking conscious action (Freire 1983).

**Figure 2.5 Framework for viewing a participatory social orientation approach to patient-physician communication (Roter 2005)**



The first stage in the model is patient participation in medical dialogue through a process of narrative reconstruction and an affirmation of self-worth and self-knowledge. This stage resembles the process of disclosure and reflection, to affirm the value of life experiences that occurs in adult learning (Freire 1983). Roter (2005) suggests that patients with poor health literacy may have problems in articulating their illness narrative.

The next stage in the model is activation for critical dialogue, through questioning, information appraisal, joint problem solving, and negotiation skills necessary for medical decision-making. This stage resembles Freire's (1983) account of dialogue and critical analysis that supports the assessment of a situation and the core conditions that have contributed to it. Roter (2005) suggests that low literate patients may lack the cognitive skills needed for the recall and comprehension of complex medical information and terminology and be less inclined to ask, question or challenge the expertise of the physician.

The final stage in the model is patient empowerment for change. This stage involves an individual making informed choices and assuming control and responsibility for the social, environmental and personal context of their current health status. This is close to Freire's (1983) process, where individuals are transformed from a passive subjects to an active participants through their appreciation that they have the ability to control and change their lives through their actions. This step reflects Freire's 'critical consciousness' and Nutbeam's (1998) critical health literacy.

### ***2.5.2 Shared decision-making***

Shared decision-making is an example of a health action that is dependent on patient-provider interaction and therefore may be influenced by health literacy.

Ishikawa and Yano (2008) suggest that the communicative skills of patients such as information seeking, information verifying and information provision are closely related to communicative or interactive health literacy. Furthermore, they suggest that a patient's degree of confidence in participating in medical decisions may be a reflection of critical literacy. However, few studies have investigated an association between health literacy and participation in shared decision-making. In a study of a computerised shared decision making intervention for prostate cancer patients low health literacy was suggested to hinder the understanding of information provided in the CD-ROM based program, and ultimately patient participation in the shared decision-making process (Kim et al. 2001). The authors suggest the link between poorer health literacy and less participation in shared decision-making may be because of the association between lower health literacy and lower prostate cancer knowledge scores after the intervention (Kim et al. 2001). However, a combination of low health literacy and low knowledge scores may not necessarily be predictive of

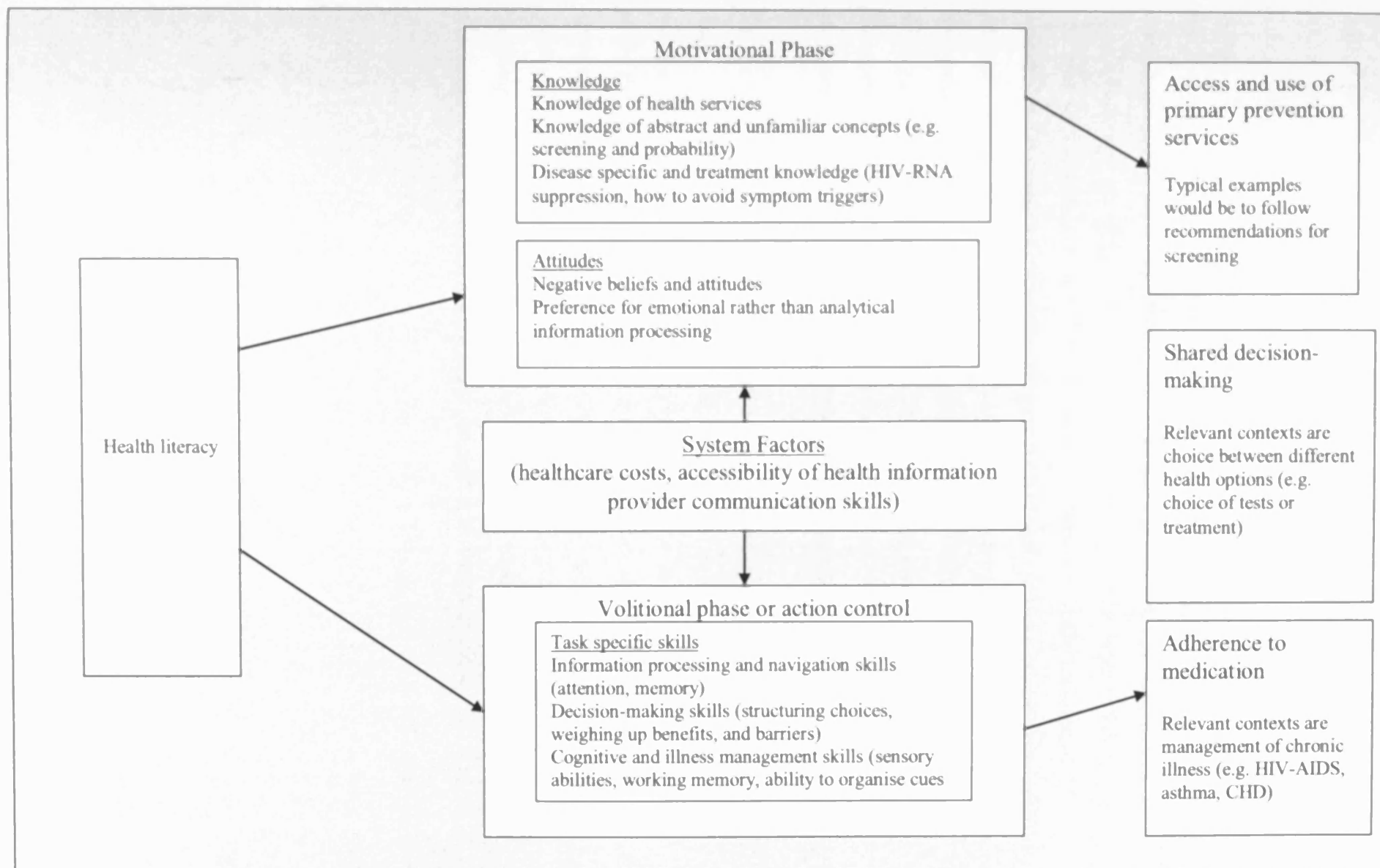
behaviour (e.g. Miller et al. 2007; Peterson et al. 2007). Thus, the pathway between health literacy and involvement in shared decision-making may be more complex than can be explained through poor knowledge scores.

Two studies have investigated a direct association between health literacy and participation in decision-making. Mancuso and Rincon (2006) reported that asthma patients with low health literacy were less likely to desire involvement in decisions about their care, even after controlling for demographic and asthma characteristics. Another study reported that low health literacy was associated with less desire to participate in medical decision making and less diabetes related knowledge; however, there was no relationship between health literacy and diabetes outcomes (Dewalt and Boone 2007). Both these studies were cross sectional and measured health literacy and literacy at the functional level. Therefore, the complexities of how health literacy may influence involvement in shared decision-making are not explained.

### ***2.5.3 Pathways between health literacy and shared decision-making***

Von Wagner et al. (2008) have developed a model of pathways among health literacy and screening use, shared decision making, and medication adherence and suggest a number of motivational barriers to shared decision making [see figure 2.6 below]. These barriers involve: the use of technical terms, complex ideas, multiple options, and the need to differentially weigh the value of unfamiliar choices. Patients with health literacy problems are suggested to be more likely to attempt to reduce the burden of making a decision by adopting maladaptive strategies and base their decisions on the most readily understood factor rather than carry out more difficult analytical information possessing (von Wagner et al. 2008).

Figure 2.6 Pathways between health literacy and screening use, shared decision-making and medication adherence (von Wagner et al., 2008)

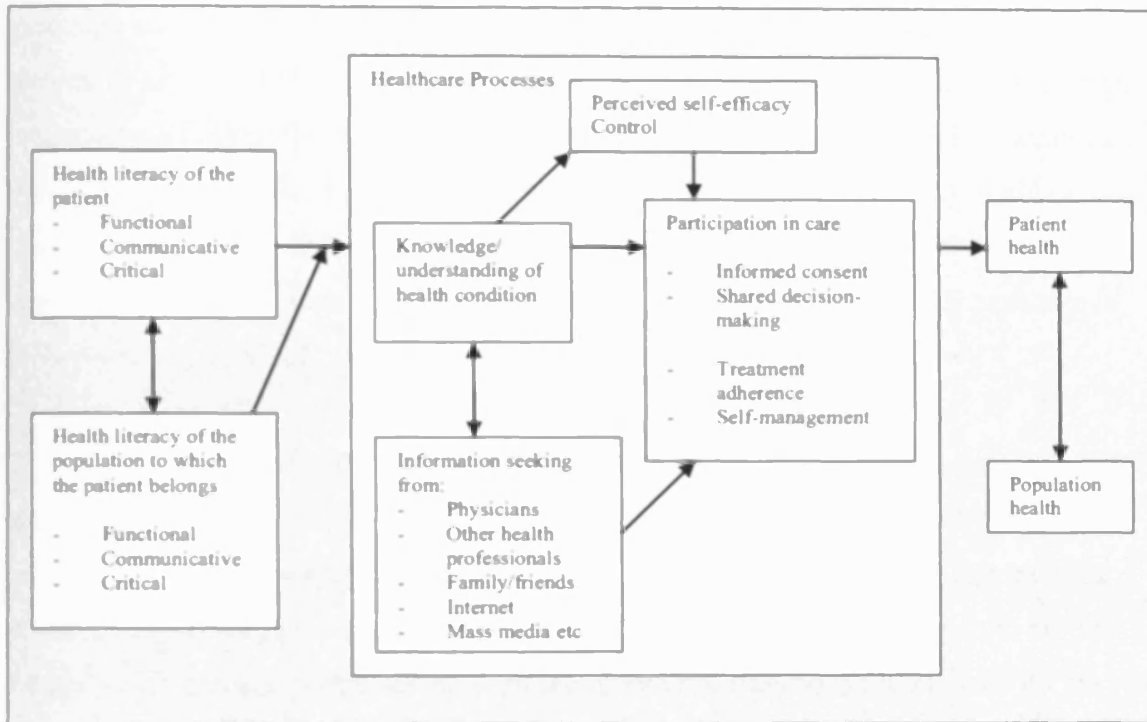


#### **2.5.4 Pathways between health literacy and participation in healthcare processes**

Ishikawa and Yano (2008b) propose a model of pathways between health literacy and a range of healthcare processes (including shared decision-making) (see figure 2.7 below). The model includes the cognitive and social skills involved in Nutbeam's (2000) three types of health literacy (functional, communicative/interactive, and critical) and shows how they interact with healthcare processes. The ways health processes operate are suggested to be as follows: when patients' have health concerns, their health literacy influences their knowledge and understanding of the problem, and influences information seeking from various sources. In the model, self-efficacy to participate in healthcare processes and perceived control of one's health are related to health literacy and influence patients' involvement in their care through making informed decisions and participating in decision-making. Patient involvement is suggested to lead to better treatment adherence and self-management and all these processes together are suggested to influence patients' health.

The model extends beyond the individual level to make suggestions on how the health literacy of the individual may interact with the population to which the patient belongs. Ishikawa and Yano (2008) suggest that a higher level of health literacy within the population may reduce the demand for individual health literacy by the appropriate communication of health information, and may moderate the relationship between individual health literacy and participation in healthcare processes by providing support for those with poor health literacy to seek and understand health information, make informed decisions and engage in self-management.

**Figure 2.7 Pathways between patient health literacy, participation in healthcare processes and health (Ishikawa and Yano 2008).**



Ishikawa and Yano's model is in its preliminary stage of development and needs empirical testing and further development. Health literacy is represented as preceding knowledge and understanding which then influences other healthcare processes such as information seeking and self-management and decision making. One argument that could be levelled against the model is that the processes appear to act in a linear way. Patients do not begin as a 'blank sheet' in terms of knowledge of their health, how to self-manage their health, and their communication with health professionals. They have prior experiences, knowledge and other capabilities that may contribute to their health literacy skills. For example, in Nutbeam's (2008) asset model, health literacy is not a starting point that precedes all other processes that lead to health outcomes, health literacy is an outcome of both individual capabilities and health education and thus goes on to influence health behaviours.

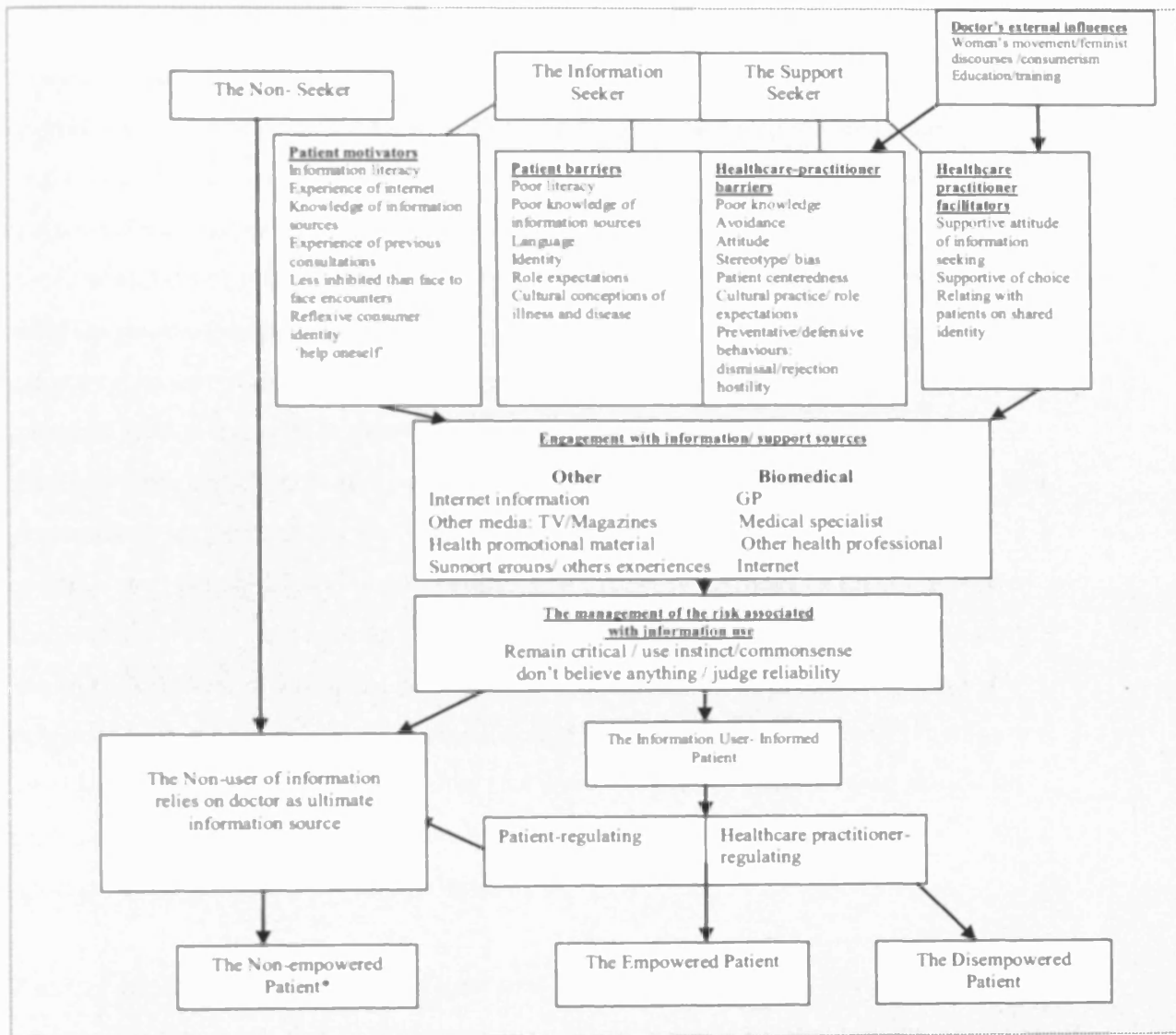


### ***2.5.5 Health literacy: an influence on information exchange, shared decision-making and empowerment***

The candidate's meta-study review to explore external influences on information exchange and shared decision-making in healthcare consultations identified health literacy as an over-arching influence and mediator of the relationship between health information seeking, the appraisal of information and the exchange of information in shared decision-making encounters (Edwards et al. 2009). Health literacy is not featured as a variable in the model but was shown to interact with a number of processes (such as engagement with information, appraisal, acceptance or rejection of information, and use of information in a consultation) (see figure 9 below).

The model demonstrates that the pathway between health literacy and patients' involvement in their healthcare is not necessarily a linear one, where health literacy precedes all other processes, as described by Ishikawa and Yano (2008) (figure 2.8). Rather, the pathway in this model appears to be a more complex and dynamic process where health literacy permeates through the model and directly interacts with all the processes. Different types of health literacy may come into play during information seeking, engagement with information, acceptance of information and its subsequent use in communication with healthcare professionals. The outcomes in this model are described in terms of empowerment (i.e. empowerment, non-empowerment and disempowerment). In order to achieve empowerment through informed decision-making sufficient health literacy skills are needed to seek, evaluate, and engage in the exchange of information. Edwards et al. (2009) suggest that if patients are unable or not motivated to engage with or gain access to health information before consultations, their opportunity to become empowered is limited. This seems to be exaggerated when there were communication barriers between them and health professionals.

**Figure 2.8 External influences on information use and patient empowerment**  
(Edwards et al. 2009)

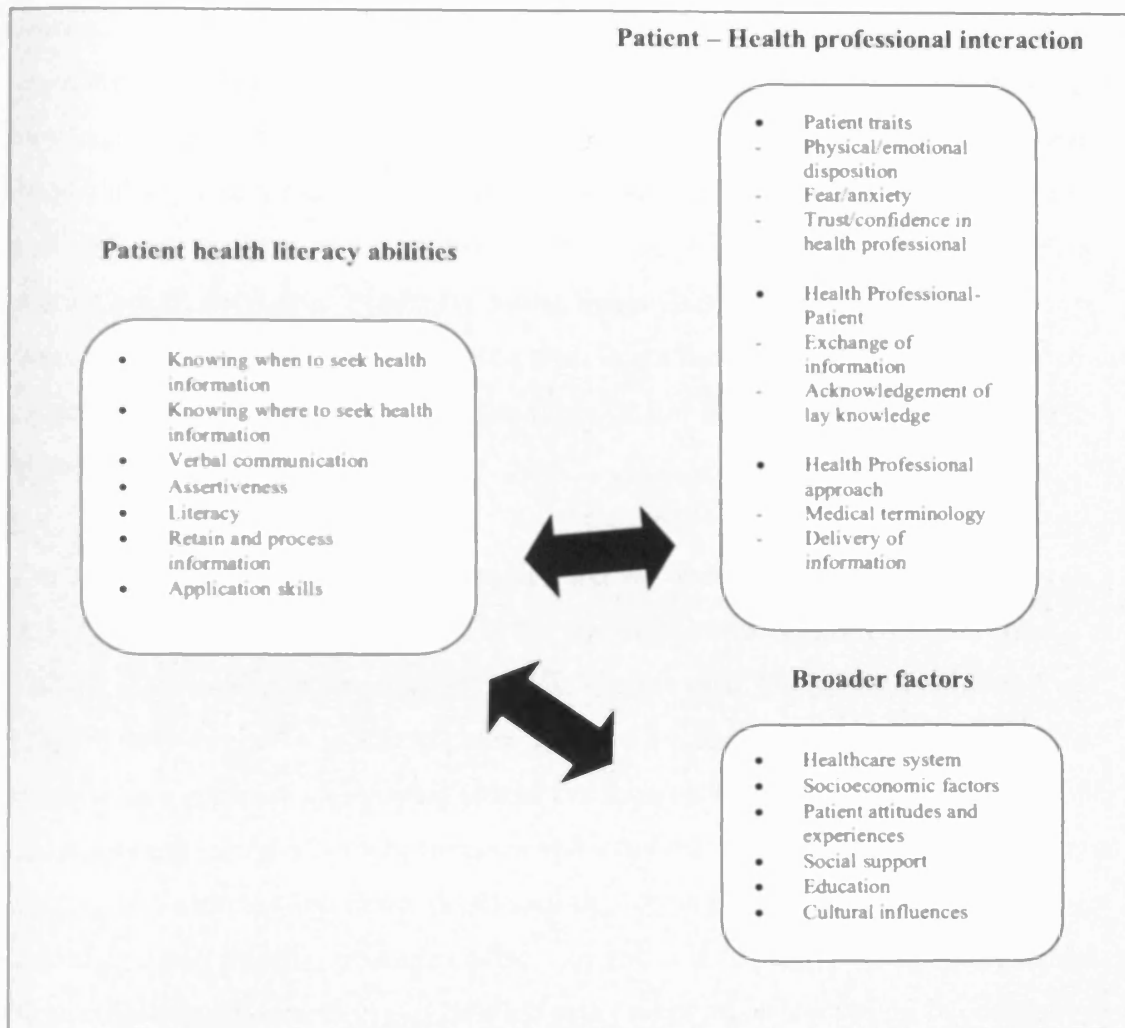


### ***2.5.6 Conceptualising health literacy experiences from the patient perspective***

Although many studies have explored abilities in seeking, understanding and using information, they do not refer to the term 'health literacy' or attempt to add to the conceptualisation of health literacy. Furthermore, few studies have attempted to capture the importance and meaning of health literacy using qualitative research methods. Such approaches may help to explore its nature and practice in more nuanced detail. However, two recent publications since the design and implementation of this study provide some insight into health literacy experiences from the patient perspective. A recent qualitative study of health literacy, the doctor-patient relationship and information giving showed that patients with both low and adequate health literacy (as measured by the REALM) felt that health information should be given to them in more simple language. The doctor-patient relationship was important to all participants and there was a need for trust (Shaw et al. 2009). If patients have psychological or social problems that prevent them forming a positive relationship with a health professional, or if health professionals do not communicate health information in ways that patients can understand, their understandings (and potential empowerment) may be compromised, irrespective of their health literacy level (Edwards et al. 2009). According to Shaw et al., (2009) information should be tailored and a range of communication methods should be adopted that are appropriate to patients' individual needs.

Another recent study sought to capture what health literacy means from the patient perspective. Jordan et al. (2010) interviewed 48 participants in Australia and identified seven key health literacy abilities: knowing when and where to seek health information, verbal communication skills, assertiveness, literacy skills, capacity to retain information and application skills. From their findings Jordan et al. (2010) produced a model that included these seven health literacy abilities, relating them also to the broader healthcare system factors that affect them (see figure 2.9).

**Figure 2.9 The patient perspective: core individual abilities of health literacy and the broader factors that affect abilities (Jordan et al., 2010)**



Jordan's model may be useful to help inform healthcare professionals about patients' health literacy abilities and help them identify patients' personal barriers that may influence whether these abilities can be developed and put into practice. On a practical level, this may help clinicians make informal assessments of patients and use particular strategies to communicate at the most appropriate level. However, the model is based on only the experiences of 48 participants in one area of Australia and may not reflect a complete set of abilities and their barriers. Further research is needed to investigate a wider range of health literacy abilities and barriers across a range of patient groups and in different health contexts.

### **2.5.7 Section summary**

Research on how health literacy affects patient-provider interaction has shown that patients with inadequate health literacy have problems communicating with health professionals. Common problems are: a poor understanding of explanations of their condition (Williams et al. 1998b), poor understanding of medication instructions and how to care for their condition (Schillinger et al. 2004). Roter (2005) suggests that those with poor health literacy may have problems articulating their illness narrative, lack skills in recall and comprehension and also have problems assuming control or making health decisions. Studies of health literacy and involvement in shared decision-making have shown that those with lower health literacy are less likely to participate in decisions about their care (Dewalt and Boone 2007; Kim et al. 2004; Mancuso and Rincon 2006).

The pathway between poor health literacy and lower uptake of shared decision making may be due to barriers such as the use of technical terms, complex ideas, multiple options and value judgments (von Wagner et al. 2008). Ishikawa and Yano (2008b) have devised a model of pathways between health literacy and participation in healthcare processes (including shared decision making). The model places health literacy as preceding all other processes and as an influence on knowledge, perceived control, self-efficacy and information seeking, leading on to participation in care, shared decision making, treatment adherence and self-management. Another model by the candidate Edwards et al. (2009) focuses more on influences on information exchange and shared decision making as healthcare processes. The model shows the complex way that health literacy influences a range of other influences on what information is sought and used outside and inside a healthcare consultation. The outcome of information use in the candidate's model is the degree of empowerment experienced by the patient, again influenced by their level of health literacy.

More recent qualitative studies have contributed to the body of mainly quantitative research by identifying how, when and to what extent participants exercise their health literacy skills (Jordan et al. 2010). Jordan et al.'s model of health literacy abilities, and the barriers identified by them and Shaw et al., confirms some of the

barriers identified by Edwards et al., (2009). However, further research is needed to understand these abilities and barriers within different health contexts.

#### ***2.6 Part Four - Patient education strategies to improve health literacy***

The idea that health literacy can be improved through health education has originated from Nutbeam's (2000) paper in which he describes how health education strategies might operate in order to improve health literacy and benefit both individuals and the community in which they live. Firstly, the goal of using education to improve functional health literacy is to communicate information through the transmission of factual information on health risks and health service utilization. This can be achieved through providing information through existing channels, from other people and from media sources. The benefit to an individual is improved knowledge of health risks and how to use health services and compliance with prescribed actions. The benefit to the community is increased participation in preventative health (e.g. screening, immunization) (Nutbeam 2000). Secondly, the goal of using education to improve interactive health literacy is the development of personal skills through tailored health communication to meet specific needs, promote community self-help and support groups, and enhance a combination of different communication channels. The benefit to an individual is the capacity to act independently on knowledge and improved motivation and self-confidence. The benefit on a community level is the ability to influence social norms and participation in social groups (Nutbeam 2000). Finally, according to Nutbeam (2000) the goal of using educational strategies to improve critical health literacy is to facilitate personal and community empowerment through providing information on social and economic determinants of health and allowing policy and organizational change. This can be achieved through the provision of advice to support community action, advocacy communication to community leaders and politicians and the facilitation of community development. The benefit to the individual is an enhanced resilience to social and economic adversity. At the community level the benefits are an improved ability to act on social and economic determinants of health and increased community empowerment,

Taking on Nutbeam's idea that health education provides an opportunity to improve health literacy, Wang (2000) aimed to show how health literacy can be increased in order to improve individual and community health, using a case study of schistosomiasis (a parasitic infectious disease) control in China. Wang (2000) describe three types of health literacy; basic health literacy (a fundamental understanding of a health problem and the ability to take actions to remedy the problem), functional health literacy (more advanced knowledge and skills and the ability to seek out information to respond to one's needs), and critical health literacy (as described by Nutbeam, 2000). Since this paper these types of health literacy have been more refined by Nutbeam (2000), basic health literacy is consistent with Nutbeam's Functional health literacy, whilst functional health literacy described by Wang (2000) appears to resemble interactive health literacy as described by Nutbeam (2000) and critical health literacy is the same as Nutbeam's (2000) description. The table below (table 2.1) shows Wang's (2000) ideas on how health education can be used to improve different types of health literacy. Basic health literacy requires a top-down approach to the dissemination of information about ideal health behaviours. Functional health literacy also requires a top-down approach but needs more educator training and skills development. Critical health literacy requires a bottom-up approach that empowers people to seek and analyse information for self-management and improved health outcomes.

**Table 2.1 Using health education to improve health literacy**

Health Education	Basic (functional: Nutbeam 2000)	Functional (interactive: Nutbeam, 2000)	Critical (Nutbeam, 2000)
Approach	Top-down	Top-down	Bottom-up
Contents	Limited predetermined knowledge	Limited pre-determined knowledge and skills	Unlimited; allow audience participation to decide
Method	Commending or manipulating	Lecturing or banking	Participatory and problem-posing
Objective	Compliance with pre-determined simple behaviour	Compliance with pre-determined behaviour in an ideal environment	Self-determined action for participants with perceived benefits in changing their health behaviours
Educator's role	Knowledge teacher	Knowledge and skills trainer	Facilitator and partner
Preparation for the educator	Limited knowledge, and advertising or propaganda skill	Limited knowledge and skills in the subject and communication in class training	Knowledge and skills to address all determinants of health in the people's environment

Wang (2000) suggests that in order to increase health literacy in the case of schistosomiasis control, the focus should be on people's behaviours. Health education strategies aimed at increasing critical health literacy are essential as they involve more than simply the transmission of information. Wang (2000) suggests that education strategies should provide information on environmental and social determinants in addition to exploring opportunities to promote policy and organisational change.



### **2.6.1 Health literacy and self-management education**

Levin-Zamir and Peterburg (2001) have examined the Clalit Health Services (CHS) in Israel and how they have incorporated the concept of health literacy as described by Nutbeam (2000) in their approach to improve the self-management skills of patients with diabetes. Their approach to health education involves the communication of information and the development of skills that enable action to address social, economic and environmental determinants of health (Levin-Zamir and Peterburg 2001).

Levin-Zamir and Peterburg (2001) discuss how Nutbeams' three types of health literacy can be applied to diabetes self-management; firstly, at the functional health literacy stage patients need to gain access to more basic information about their condition and how to use health systems to manage it. Patients with diabetes need to acquire skills to control their disease and need to understand the importance of the lifestyle changes they may need to make. However, Levin-Zamir and Peterburg (2001) suggest that it is not always clear to people how they may do this. Mastering the skills needed to manage their diabetes requires information that is readily accessible and understandable. Levin-Zamir and Peterburg (2001) relate the way CHS have developed a health education kit for diabetes to the development of functional health literacy. The kit helps patients become health literate by providing separate information pamphlets for each area of self-management, a diabetes identity card and self-care record, and a video cassette for home viewing that demonstrates foot-care and self-injection of insulin, and also testimonials of the experiences of others. Secondly, at the interactive health literacy stage the CHS approach is to encourage patients to share information with others and to teach patients how to communicate in order to gain support. Another element of the CHS approach that reflects interactive health literacy is their plan to help people understand and have some influence over factors that affect their health, and train professionals in ways of communicating that promote empowerment rather than compliance. Finally, at the critical health literacy stage the CHS is looking for ways to help people critically evaluate appropriate information.

Levin-Zamir and Peterburg (2001) conclude that using the concept of health literacy to guide the development of self-management skills may be beneficial to achieving good health outcomes, which in turn is beneficial for both individuals and the health system. They suggest that patients require a level of health literacy that enables them to critically analyse information on their own and make decisions regarding their care.

### **2.6.2 Research evidence**

There has been little empirical research from the perspective that health literacy may be improved through health education. Much of the research has focussed on how inadequate health literacy affects knowledge outcomes after patient education (e.g. Williams et al. 1998b). However, Renkert and Nutbeam (2001) have examined the possibility that there may be an improvement of maternal health literacy through antenatal education. Maternal health literacy is described as:

**“the cognitive and social skills which determine the motivation and ability of women to gain access to, understand, and use information in ways that promote and maintain their health and that of their children” (Renkert and Nutbeam 2001 p.382)**

The study explored the feasibility of using the concept of health literacy to guide the content and development of antenatal classes. This was done by focussing attention on the development of skills and confidence to make choices that improve one's health, rather than simply the transmission of information. The aim was to explore whether critical health literacy could be achieved and whether an individual is able to seek out information and use it to exert control over health determinants and make informed choices. A series of interviews and focus groups included a range of health professionals, pregnant women and new mothers. The questions were developed using health literacy as a guiding framework and explored how much the content and delivery of the teaching and learning in the classes supported the development of knowledge, skills and confidence to act in ways that represent health literacy as described by Nutbeam (2000). The findings were that the antenatal education helps prepare mothers to achieve successful childbirth by following established procedures of the institution in the study. However, time limitations affected the teaching methods and classes covered mostly the transfer of factual information, rather than the

development of decision-making skills and practical skills which better reflect the concept of health literacy. Renkert and Nutbeam (2001) suggest there is scope to develop the content of the delivery of antenatal education in ways that better reflect health literacy. In this study health literacy is presented as an outcome of antenatal education and fits with Nutbeam's (2008) asset model [see figure 2.2]. A focus on improving health literacy through antenatal classes can help shift the educational focus from transferring *knowledge* to teaching women *skills* that can empower them to make informed choices.

### **2.6.3 Section summary**

Nutbeam (2000) suggests that health literacy can be improved through health education, which would benefit both individuals and the community in which they live. Wang (2000) has proposed ideas on how different types of health literacy can be improved through health education, with basic and functional health literacy requiring a top-down approach and critical health literacy requiring a bottom-up approach. Levin-Zamir and Peterberg (2001) have discussed how the concept of health literacy may apply to diabetes self-management and how it can be used to guide the development of skills that may lead to positive health outcomes. Renkert and Nutbeam (2001) investigated the development of maternal health literacy through antenatal education classes. However, the classes gave more factual information and not skills that are reflective of health literacy. Renkert and Nutbeam (2001) suggest there should be a shift in the educational focus to reflect the development of health literacy, especially critical health literacy which is most pertinent to women's informed choices about their pregnancy, child birth and child care.

## **2.7 Discussion of chapter**

Health literacy has evolved from an early description that was more reflective of the reading ability and comprehension required to understand available health information to a more action oriented description where health literacy enables people to understand health information *in order to* carry out actions that may benefit their health. These actions include: adhering to medication, making lifestyle changes, making informed decisions about managing one's health, and sharing information and participating in decision making about treatments with a health professional. At a conceptual level there are different facets of health literacy that contribute to a person's overall health literacy, for example functional, interactive and critical health literacy which are suggested to be progressive (Nutbeam 2000) and fundamental, scientific, cultural and civic literacy which are more reflective of the multi-dimensional nature of health literacy (Zarcadoolas et al. 2003). However, many of these facets are overlooked in the measurement of health literacy and the most utilised tests (REALM and TOFHLA) remain focused on the more functional aspects of health literacy which originate from earlier conceptions of health literacy.

The prevalence of inadequate and marginal health literacy is a concern, especially in the United States (Paasche-Orlow et al. 2005). However, most research has involved measuring health literacy in samples of patients recruited from clinics and hospitals. Less is known about health literacy in a general population. Furthermore, with such a strong research focus on objective measurements of health literacy, there is a gap in knowledge of how health literacy is put into practice by patients and how well different aspects of health literacy are performed across different health contexts. The effect of health literacy on knowledge of chronic conditions and health outcomes is complex; in some cases health literacy appears to be a predictor of patients' knowledge (Kalichman et al. 2000; Williams et al. 1998a). However, cross-sectional studies using measures of knowledge and measures of health literacy have not always reported a negative effect of low knowledge and low health literacy on the self-management of chronic disease and health outcomes (Fang et al. 2006; Kim et al. 2004). Thus, there must be ways in which people are successful in managing their condition that are not reflected in these measures.

Causal pathways between health literacy and health outcomes are currently not well established. Although Paasche-Orlow and Wolf (2007) have suggested a model of causal pathways, their model is based on a review of cross-sectional research and is subject to the same problems with sampling and research designs.

It is clear from studies of health literacy and patient – provider interaction that inadequate health literacy has an effect on communication in healthcare encounters and particularly on shared decision making (Kim et al. 2001; Mancuso and Rincon. 2006). The pathways between health literacy, and communication and participation in healthcare consultations are only just beginning to be understood and more empirical work is needed to test current review-based and theory-based models.

Nutbeam's conceptualisation of health literacy and his idea that health literacy can be improved through health education, and the teaching of self-management skills have been useful in the development of educational strategies at both individual and community levels. However, these concepts are at present not widely applied to health education and there is a need for empirical research to substantiate Nutbeam's conceptual view of health literacy and the effectiveness of effects to improve it.

Finally, some features of health literacy that are included in the definitions reviewed earlier are significant to the aims of this thesis. These features are:

- health literacy as a *capacity* (IOM 2004)
- health literacy as a *process* (Mancuso 2008)
- health literacy as an *outcome of health education* (Nutbeam 2000)
- health literacy *evolves over time* (Zarcadoolas et al. 2006)
- health literacy represents *making sound decisions* in a range of *settings* (Kickbusch and Maag 2008)
- health literacy is important in *health contexts* and *across the life-course* (Kwan et al. 2006)

The combination of these features may provide a more integrated description of health literacy and the contexts in which it is practised. The remainder of this thesis will explore the meaning of health literacy from the perspective of patients with a long-term condition and examine how they develop health literacy over time, across a range of health contexts and through patient education.

## **3.0 Methods Chapter**

### **3.1 Introduction**

This chapter is divided into two main sections: the first will give an overview and rationale for the research design, and the second part will describe the recruitment settings and procedures. There will be a detailed description on how the data were collected and managed from the interview and observation period through to the final stages of analysis. The research design and methods will be summarised at the end of the chapter. There will be a detailed discussion of the strengths and limitations of the methods in chapter 8 (Discussion chapter).

### **3.2 Section one: Research design**

The main aim of this thesis is to explore how health literacy is practised across different health contexts (i.e. situations and activities relating to health) and how people with a long-term health condition might develop their health literacy through learning skills taught in patient education programmes and from self-directed learning.

One possible way of studying the development of health literacy would be to take a measure of health literacy at one point and then repeat the measure at a second time point. However, measures of health literacy are problematic and seem to be a better measure of basic literacy or very narrow definitions of health literacy. There are many studies that have used quantitative methods to study the relationship between inadequate health literacy and health outcome measures or to study the effect of inadequate health literacy and health knowledge after an education based intervention. Only one recent study has tried to capture how health literacy is experienced and practised from the perspectives of patients (Jordan et al. 2010). Hence, there is a need for further qualitative research on patients' health literacy experiences and practices.

The measurement of health literacy was not important for the current research. The focus was more on the learning methods and interactive processes that may facilitate the development of health literacy over a time period and potentially influence the exchange of information and shared decision-making in healthcare consultations. A longitudinal qualitative approach to data collection and analysis was chosen as an appropriate method to investigate the development of health literacy because of its utility in exploring evolving and complex processes, and because it helps researchers develop the ongoing relationship with a participant that is necessary to explore sensitive topics (Murray et al. 2009).

### ***3.2.1 Participant and non-participant observation***

Observation methods provide researchers with an opportunity to see what takes place in a setting rather than relying on participants' memories and interpretations (Patton 1990). They also allow researchers to address research problems that require knowledge of practice (Lambert and McKevitt 2002). Two different types of observation are used in qualitative research. These are 'observing without participating' (or non-participant observation) and 'participant observation' (Hansen 2006). Researchers often move between the two types within one research project. The extent of participation is described by Patton (1990) as a continuum with a great deal of variation. According to Hansen (2006)

**"the level of participation that is desirable or possible will vary accordingly to the purpose of the research, the nature of the research setting and the characteristics of the researcher".**

The qualitative approach used in this thesis entailed both participant and non-participant observation of patients undertaking a patient education programme. The objective of carrying out these observations was to capture how health literacy may develop through education and social interactions between participants during the classes. One aim of the observation component of the research was to provide a background to the patient education settings and help guide relevant interview questions.

### **3.2.2 Serial Interviews**

Conrad (1990) suggests repeated interviews are particularly appropriate for studies of chronic illness experiences as they permit process and change to be captured and examined in depth. A team of researchers in Scotland found using repeat interviews helpful to capture newly diagnosed patients' emotional reactions about diagnosis, views about information provision at the time of diagnosis (Peel et al. 2004), and perceptions of their disease and health services (Lawton et al. 2005) .

The use of repeated interviews was selected as an appropriate method for this study to investigate the development of health literacy and identify changes in attitudes, knowledge, and experiences over time. Although the use of focus groups is popular in social research to investigate experiences, attitudes and opinions, it was not considered for this research because people's accounts of illness, experiences with health services, understandings of their own health and engagement with health information are deeply personal. Some people may be embarrassed to have a low understanding or have insufficient literacy abilities which prevent an in-depth understanding of their own health (Parikh et al. 1996). Hence, a single interview or a focus group may not facilitate discussions about such personal barriers that may affect health literacy. Serial (repeated) qualitative interviews was seen as a method by which to build and develop rapport with participants and allow discussion of such sensitive and personal issues (Murray et al. 2009).

Four participant groups were selected for the study: patients undergoing a cardiac rehabilitation course that entailed a 6-week exercise and education programme, patients undergoing a 6-week diabetes education programme, patients undergoing a six week long-term condition "self management programme", and a group of participants who had not undertaken any patient education or self management education. Four different groups were chosen in order to make comparisons across health contexts and between those who receive structured education about their condition and those who may be more self-directed learners. The programmes studied in this thesis were chosen because they all provided structured education components for two to two and a half hours per week for approximately six weeks. Other programmes were considered such as the self-management programme run through



Arthritis Care. Patients with arthritis would have been a suitable group to study but there was not a programme available in the research location.

The aim of interviewing participants in the patient education groups was to find out what they understood about their condition before the patient education course, how and what they had learned after the course had finished, and how they may have used their learning in their communication with health professionals in the following 12 weeks. The aim of interviewing the community group was to find out what they understood about their condition at the first time point and to see if, and how, they had learned any more over a time period.

### ***3.3 Section two: procedures***

The methods and procedures used for this thesis will be described under the main headings of:

- recruitment sites;
- recruitment procedure;
- observation procedure;
- interview procedure;
- interview data;
- method of analysis.

#### ***3.3.1 Recruitment sites***

##### ***Cardiac Rehabilitation Course***

The first research site was a Phase III Cardiac Rehabilitation programme operated by the Cardiology department of a university hospital and run by nurses and physiotherapists at a leisure centre. The Cardiac Rehabilitation programme is offered to patients who have had a heart attack or heart surgery. The aim of the intervention is to facilitate a return to normal living and to encourage patients to make lifestyle changes in order to prevent future cardiac events. There are four phases, Phase I takes place when the patient is in hospital, Phase II is at the convalescent stage following discharge from hospital, Phase III is a supervised out-patient programme and Phase IV includes long term maintenance. Participants for this study were recruited prior to Phase III of the programme where they were going to undertake weekly exercise,

relaxation and education about the benefits of physical activity, diet, stress management, medication and coronary disease risk factors. Each weekly class was two and a half hours long and comprised a one hour lecture in a lecture room, a one hour exercise class and half hour relaxation in studio within the centre. Classes were observed by the student for 6 weeks duration and covered all components of the education part of the programme. Four exercise classes were observed and the student participated in one of the exercise classes.

### *Diabetes Education Programme*

The X-PERT diabetes education programme is a 6 week structured patient education programme operated by Local Health Boards (equivalent to Primary Care Trusts in England) and mainly delivered by a course tutor (trained diabetes nurse) with the assistance of other community nurses. The programme is based on the theories of patient empowerment, patient centred care and activation ([www.xpert-diabetes.org.uk](http://www.xpert-diabetes.org.uk)). The aim of the programme is to improve diabetes control, reduce diabetes tablets/insulin, increase self-management skills and improve lifestyle and quality of life. Some of the contents of the course include identification and management of symptoms, understanding results, healthy eating managing carbohydrates, study of food labels, and complications of diabetes.

Patients were recruited to the class by advertisements in the local paper and information given out by nurses at their GP surgery. The Local Health Board held a list of patients wanting to participate in the course and would invite approximately twenty people and expect to get around twelve people to attend each course. The student acted as a participant observer for 5 of the 6 weeks duration and covered all but one component of the programme. Further details of the programme appear in Chapter 7.

### *Self-management Education Programme*

The Expert Patient Programme (Wales) is a 6 week NHS and Welsh Assembly Government funded self-management course run by the Local Health Board is typically delivered by a course leader and a lay tutor (both non- health professionals). The aim of the programme is to help improve patients' quality of life by learning different skills to better manage their condition on a daily basis. The course is based on the Chronic Disease Self Management Programme (CDSMP) (Lorig et al. 1986).

The contents of the course include learning skills to: manage symptoms, deal with stress, depression and low self-image, manage pain, relax, eat healthily, work more closely with carers, and plan for the future ([www.eppwales.org](http://www.eppwales.org)). The Local Health Board had a waiting list of patients wishing to undertake the course and would invite a number of people and aim to get about 8-16 patients to participate. To be eligible for the course patients had to be over 18 and living with a long-term health condition which they have had for 12 months or more. Patients were recruited to the classes through local advertisements and leaflets placed in GP surgeries, hospitals and community centres. The student acted as a participant observer in all 6 sessions of the course.

### *Comparison Group*

Participants were recruited from a community adult education centre where a wide range of courses were delivered.

### *3.3.2 Accessing recruitment sites*

Accessing participants on the X-PERT diabetes programme and the Cardiac Rehabilitation Programme was organised through the course leaders. Meetings were set up and the student discussed the research protocol with them. They agreed for participants to be recruited from their groups and made suggestions about how this could best be done.

Accessing participants on the Expert Patient Programme was more difficult. An agreement was reached with the course tutors to carry out the research in one of their groups. However, this had to be re-negotiated at a higher level at a later stage with the person who was in charge of the programme in the Welsh Assembly Government at that time. There were concerns over the course being observed and the privacy and confidentiality of the participants. Further concerns were that the participants would not talk openly as usual with a researcher present or that people would drop out or not start the course if they knew a research student was present in the group.

Two meetings were held between the student, a PhD supervisor and the person in charge of the Expert Patient Programme to negotiate access terms, and after agreeing to the terms set out by the person in charge of the programme access was allowed. These terms were that the student acted as a participant and took no notes in the classes.

Access to the comparison group was through a person responsible for adult education in the local area. The student met with this person to discuss the research protocol and it was agreed that the adult education centre would pass on information packs to potential participants.

### ***3.3.3 Ethical considerations***

The Research Ethics Committee for Wales granted ethical approval for the study, Reference number 08/MRE09/54 (see appendix 1).

Below are some of the ethical issues that occurred during the research:

- The course tutor for the Expert Patient Programme did not want to identify the student to the rest of the group but after discussing that it was not good practice to do that, she agreed to identify the researcher and explain the student's role.
- The student sometimes witnessed instances where participants seemed agitated and uncomfortable in a patient education class. The tutors delivering the particular class seemed to have an abrupt manner at times and were quite forceful in getting participants to take part in activities that they found difficult. As a participant observer it was difficult and sometimes distressing to witness such events and not comment or intervene. It would have upset the tutors if the researcher had commented about their behaviour or offered support to the people who seemed agitated. The issue was discussed with a PhD supervisor, who offered support and advice on how to deal with such situations.

- Participants who did not respond to first contact for further interviews were contacted three times over several weeks before a decision was made that it would not be ethical to pursue them for further interviews.
- One participant (3EP) had her 14 year old daughter present in the room during two interviews. It was her daughter that had the serious condition and the interviewee was being interviewed from a parent/carer perspective. The participant talked about the severity of her daughter's condition (which was potentially life-limiting) and her frustrations with healthcare services whilst her daughter was in the room. Although the participant and her daughter appeared comfortable throughout these interviews, the daughter's presence sometimes made it difficult and distressing for the student. Hence, interviews were sometimes shorter than expected. This issue was discussed with PhD supervisors and the third interview was arranged at a time that the daughter was in school. The student was much more relaxed during the interview and the interview was longer than previous ones and more topics were discussed.

### ***3.3.4 Recruitment procedure***

#### ***Patient Education Groups***

Prospective participants were initially informed about the research by the course leaders; they were then asked if they would like an information pack. The course leaders then mailed an information pack directly to the participant. The information packs comprised an invitation letter, booklet containing information about the research and details of the requirements of participants and a consent form to be signed and returned to the researcher in a prepaid envelope (see appendix 2).

#### ***Comparison Group***

Prospective participants were initially informed of the research by a person who was in charge of delivering a course at an adult education venue. A relevant information pack was passed on to those who expressed an interest (see appendix 3). Three participants were recruited from the adult education venue and one further participant was recruited through personal contacts.

### ***Inclusion criteria***

All participants were over 18 and had a long-term health condition. A long-term condition is defined in this thesis as a physical or mental health condition that a person has lived with for 12 months and/or a condition that requires management for at least another 12 months. These criteria were used based on the criteria for long-term conditions recognised by the Expert Patient Programme.

### ***Exclusion criteria***

Participants under the age of 18 were excluded from the research. There was no upper age limit.

### ***3.3.5 Participants***

It was expected that the X-PERT Programme and the Expert Patient Programme would have 8-12 attendees and the students aim was to recruit at least half of the attendees (4-6) into the interview component of the study. Sixteen to twenty-four participants were deemed a manageable amount for the longitudinal design of the research and the time frame for data collection. Eighteen participants agreed to take part and were included in the study: five Cardiac Rehabilitation programme patients, four X-PERT diabetes patients, five Expert Patient Programme patients and four from a Comparison Group. There were thirteen females and five males in the sample. The demographic characteristics of the sample will be described further in results chapter four.

### ***3.3.6 Informed consent***

#### ***Patient education groups***

The consent form in the information pack distributed to the participants asked for consent to observe them within their patient education class and also for them to take part in three audio recorded interviews. There were three options available to participants: they could consent to be part of the observation and interviews, to just participate in the interview part of the study, or opt out and not be part of the observation or interviews (see appendix 2). Those who opted out were not observed during the classes and no notes were taken about them or any of their interactions. However, the student did interact with these people during the classes in general conversations. All participants who consented were reminded at each stage of the

research that they could change their minds about their participation at any point during the process, without need of an explanation.

#### *Comparison group*

The consent form for the comparison group asked participants to take part in two audio recorded interviews, one at the beginning of the study and another 3-6 months later (see appendix 3).

#### *3.3.7 Responses*

- In the cardiac rehabilitation group it is not known how many potential participants refused to take part. The cardiac rehabilitation nurses distributed the information packs to a number of patients over a two week period. Once the five participants consented it was not necessary to recruit further participants to interview. However, the course was a rolling programme and there were new attendees joining every week. The new people attending the group were made aware of the student's presence at the classes, but were not part of the research and were not being observed.
- In the diabetes education programme five people consented to be observed and interviewed. There were three people in the group who were happy to be observed but declined to take part in the interviews. No one wanted to be totally excluded from the research.
- In the self-management education programme there were originally five people from a group of eleven who wanted to be included; all others consented for the student to make observations in the classes.

### **3.3.8 Withdrawals**

- There were no withdrawals from the cardiac rehab group.
- One participant withdrew from the diabetes group after week one due to illness. This participant was not contacted for interviews due to the seriousness of his illness and because he was still likely to be ill when the course was finished.
- In the self-management group a large number of people who attended the first day of the course did not return again. However, there were two people who withdrew from both the classes and the research: one elderly lady with sarcoidosis who unhappy with the style of the classes and felt that she had managed her condition well for 50 years and was looking for more social interaction; and another person who had anxiety problems and had constraints on his time which led him to withdraw. These people were contacted and invited to remain in the study and be interviewed but both declined. Subsequently there were three remaining participants within the group. Two further participants were recruited from another class in the same area with the help of the course tutor. One participant withdrew from the course after week three because she had to have surgery. However she wished to remain a research participant and was interviewed twice. Another took part in the first interview but did not respond to contact messages for further interviews. It was decided that for ethical reasons it was not appropriate to continue to approach him for any further interviews.
- One participant in the comparison group failed to attend an appointment for the second interview and cancelled a third time. A decision was made not to pursue the participant for further interviews after the participant failed to make contact to re-schedule.



### *3.3.9 Observation Procedure*

The research commenced with the observation of a six week patient education course. The aims of the observations were to examine interactions between participants and between participants and the course leaders. The student was looking for evidence of participants sharing information and potential learning opportunities (informally through exchanging information with each other and in a more formal way through the material being taught in the course). Although the student had ideas about what types of behaviours would be of interest, the method of gathering observation was less 'structured' to begin with and became more structured over the course of the research. At times the student engaged in 'priority observation' (Carspecken 1996), where the focus was on one or two participants or only participants who were included in the interview phase. People in the group who had agreed for the class to be observed but did not wish to be interviewed were observed but sometimes to a lesser extent than others. The student engaged in general conversations with those who had consented for the researcher to be present but did not want to be included in observations. However, no notes were taken about them. They were reminded and assured of this before the research and on meeting the student in the class.

The layout of the classes and the style of delivery sometimes presented a challenge to observing informal conversations between participants. For example, the cardiac rehabilitation class was set out like a lecture room and the researcher sat to one side of the class, only some conversations could be observed. The observations were easier in the other programmes because the class sizes were smaller and seating was arranged around a large table. Due to the nature of the research setting and the preferences of the programme organisers, each programme required a different level of observation. Thus, the extent of participation and observation in the programmes was varied (Hansen 2006; Patton 1990).

### *Cardiac rehabilitation classes*

The layout, size and delivery of the Cardiac Rehabilitation education classes were more amenable to more non-participant observation. There was much less active involvement in activities than with the other programmes. However, the student did speak with some participants throughout the observation period and participated in one activity. The student attended a weekly class over a period of six weeks at a leisure centre lecture room and sat to one side of the room to listen to the class and took brief notes about what was being taught and some of the comments raised by participants. The second part of the class was an exercise class and the student sat by the side and took notes for the first two weeks. On the third week the student took part in the circuit based exercise class after a suggestion from some of the participants. During this time observations of conversations between participants were made, and the student also engaged in detailed conversation with one participant who she was paired with as an exercise partner (participant 4CR). There were also conversations with the nurses and physiotherapists leading the class and monitoring the cardiac patients.

### *Diabetes education classes*

The size and delivery style of the programme enabled the student to adopt a more 'participant observer' role. The researcher was more highly engaged in activities within the group. Weekly class were attended over a six week period at a church hall and notes taken on the content of the education class, teaching materials and the methods of teaching used and comments and questions that were raised by the nurses leading the class and by the participants in attendance. There were also notes taken of general conversation amongst participants and between them and the nurses who were leading the class. Although the student did not have diabetes and had limited knowledge of diabetes at the start of the course, she learned alongside the participants and was included in quizzes and exercises and participated in all the group's activities.

### *Self-management classes (EPP)*

These were weekly classes attended over a six week period. In agreement with the programme organisers, the researcher engaged in 'full participant observation'. Thus, the student participated in the class as a person with a real long-term condition (asthma) and engaged in all activities. The student's condition was declared to all participants and she sat amongst them and completed all components of the programme (including: paired exercises, free think exercises, action planning and group discussions). The student took notes about the content and delivery of the education class, the general atmosphere and some comments from the participants. The course leaders did not wish for many notes to be taken so note taking was minimal and more discreet. Further notes were written up immediately after leaving each class.

### *3.3.10 Approach to individual qualitative interviews*

Qualitative interviews were considered as the most appropriate method for gathering data to inform an understanding of how patients with a long-term condition have developed knowledge and understanding about health in general, their health own concerns, and also how they use their understandings in managing their health and participating in healthcare consultations. The approach taken was a semi-structured interview in a relaxed and conversational style. This method was considered the best way for the student to build rapport, listen carefully and allow pauses and time to think (for both the student and the participant).

The interviews were carried out using an approach which has been described by Snape and Spencer (2003) as 'empathetic neutrality'. The approach emphasises that although the research is shaped by the researcher's own background and interests, the researcher should remain objective and neutral throughout the interview process. This style of interview requires the researcher to avoid talking about their own experiences, and avoiding confirming or disagreeing with the participant's opinions during the interview. This was challenging at times because some participants sought approval for their views and experiences. The student overcame this challenge by showing empathy in using phrases like "I understand how you must have felt about that" and "I know what you mean". It was difficult not to relate to participants' experiences on a more personal level. There were occasions where the student did comment briefly and

in an empathetic way that she had a similar experience or did not always understand some health information. This may have compromised objectivity but helped the student build rapport with the participants.

Building and maintaining rapport with participants was important for a number of reasons: (1) for obtaining an in-depth description of participants' experiences, (2) to conduct the research within good ethical guidelines, and (3) to ensure that participants remained interested in participating in the research. Several strategies were used to enhance the researcher-participant relationship. These included:

- Engaging in general conversation with participants within the education classes before the initial interview stage. By the time of the interview participants were familiar with the student and had met on one or two prior occasions.
- At the beginning of the interview there was some general conversation about everyday life and topics other than the research questions (e.g. family, work, studies). This was aimed at making participants feel more at ease before moving on to the research topic.
- The student engaged in short conversation with family members or others who were present at the interview location.
- Participants were reminded at the start of the interview that their responses would be confidential and anonymous throughout the research process.
- The student maintained good eye contact throughout the interview and showed genuine interest in participant's responses.
- Participants were reminded that their views and experiences were interesting and there was no right or wrong answer.
- Participants were offered comfort breaks and the student checked throughout the interview that the participant was comfortable.
- At the end of each interview the student thanked the participant and engaged in more general conversation (off-tape), before reminding the participant of the approximate timing of the next interview.
- During the observation period there was more time to build rapport with participants before their second and third interviews.

### 3.3.11 Qualitative interview procedure

All participants who consented to be interviewed were contacted by telephone in advance to arrange a convenient time and location. Participants were given information about the purpose of the interview and what it would entail over the telephone; they were also told how long the interview was expected to last (about 30-60 minutes). Participants were also reminded of these details in addition to their right to withdraw and their anonymity before the interview commenced and the tape recorder was switched on.

Interviews took place in a location of the participant's preference; this was the home of the participant on all occasions except for two participants who did not wish for the student to attend their home. One participant came to the research office at the university hospital campus and another preferred to be interviewed at the location of the education classes. Another participant came to the research office for one interview because it was convenient to her because she had a hospital appointment that day. The interviews were carried out in groups of four or five (for example, five cardiac participants were interviewed over the initial period and then four diabetes participants in the second period) and in phases (first, second and third interviews). The interviews were conducted using a semi-structured approach. Table 3.1 explains the aims of each interview phase.

**Table 3.1 Aims of each interview phase**

Interview Phase	Aim of interview
Interview 1	<ul style="list-style-type: none"> <li>• To explore what health literacy means to patients with a chronic condition</li> <li>• To explore how understandings and abilities presented by patients relate to their health literacy practices</li> <li>• To explore experiences with health literacy in the health contexts which they encounter in their everyday lives</li> <li>• To find out what barriers and facilitators participants are faced with</li> </ul>

<b>Interview 2</b>	<ul style="list-style-type: none"> <li>• To explore what new knowledge was learned in the education course and how it was learned</li> <li>• To explore the value of what was learned</li> <li>• To explore if there were any behaviour or attitude changes after the education programme</li> </ul>
<b>Interview 3</b>	<ul style="list-style-type: none"> <li>• To explore patients' experiences of interactions with healthcare providers following participation in a self management programme</li> <li>• To explore how patients experience information exchange and involvement in shared decision-making in healthcare consultations following participation in a self-management programme</li> </ul>

Although, a general set of questions were asked to all participants in all patient groups, the interviews sometimes included specific questions for their condition. For example, cardiac patients were asked questions in relation to some of the tasks and information that they needed to understand and manage their condition in particular (see appendix 4 and 5 for examples of the initial interview guides). Sometimes participants were told that the study was about health literacy and a brief explanation was given (e.g. ability to seek, understand and use health information). In general, participants were told that the research was about how they sought and understood health information, their understanding of it, what they did with information and how they communicated with health professionals.

Although the original set of interview questions were more structured to begin with, they evolved as new topics of interest arose within and across the groups of participants. Responses from one group of participants were used to inform the development of the interview questions for the next group, and so on. This iterative process of data collection was similar to that used by Dovey-Pearce et al. (2007) for their framework approach in a study on the influence of diabetes upon adolescent and young adult development. Dovey-Pearce et al. (2007) developed an 'initial thematic framework' after transcribing, sifting, charting and sorting data from their first set of

interviews into broad themes. They used their thematic framework to guide and refine further interviews.

Eighteen participants were interviewed from four sample categories (cardiac rehab, diabetes, self-management, and comparison) and three interview phases. Interview times ranged from approximately 30 minutes to 65 minutes. Participants who had taken part in the education programmes were interviewed three times (after week 1 of the programme, approximately two weeks after the programme, and 12 weeks later), participants from the comparison group were interviewed on two occasions (at an initial time point and then 12 weeks later). Arranging second and third interviews was sometimes difficult due to the data collection period being over the summer period; times between the interviews varied slightly between participants. Some participants in the education groups were unavailable for interview 2 and so their second interview was combined with interview 3. In total, there were 42 interviews (see appendix 6).

### *3.3.12 Transcriptions*

All interviews were transcribed verbatim by the student in order to help build a close knowledge of the data. This way of transcribing is aimed at representing the precise words that were used within the interview and focuses on what was said rather than the way in which it was said. Interviews were transcribed as soon as possible after the interview had taken place. In a similar method Dovey-Pearce et al. (2007), each interview in one patient group (e.g. cardiac patients) was transcribed before the interviews with the next patient group (e.g. diabetes patients) interviews commenced. Notes were made alongside the transcribing process and were used to refine the following set of interviews within a particular group (e.g. phase one and phase two) and to introduce new questions to other groups (e.g. diabetes group).

This process helped ensure that all the interviews covered all topics across all the participants, covered a broad range and depth of information, and were reflexive upon and responsive to issues being raised by the participants within and across groups (Dovey-Pearce et al. 2007).

### ***3.3.13 Data management***

The interview data were entered into the qualitative analysis software programme NVivo 8 for storage, coding and indexing purposes.

## ***3.4 Method of analysis***

### ***Considered Methods***

A range of qualitative analysis methods were considered for the design of the research. A grounded theory method would be a suitable method for producing findings that are guided by or grounded in the data (Hansen 2006). However, health literacy is a new and evolving concept and the theories and models of health literacy have not been scrutinised enough. The overall aim of this thesis was to develop the concept further through exploration of participants' experiences and understandings of health alongside extant theories and models of health literacy.

A grounded theory approach would have only allowed the researcher to work with theories that emerge from the data and so was not selected to be used in the current research. There was a need for a deductive element in the approach to analysis that was consistent with the framework approach (Ritchie and Spencer 1994).

### ***The framework approach***

The framework approach is a method by which there are pre-identified issues that the researcher wishes to investigate, but allows flexibility for new themes (Ritchie and Spencer 1994). Although it is mainly inductive, it also allows for the inclusion of both *a priori* and emergent concepts and is therefore partly deductive (Pope et al. 2000).

The data collection process is more structured than some other forms of qualitative research methods such as grounded theory, and the analytical processes in a framework approach tend to be more explicit. The framework approach stems from applied policy research with its central aim of providing recommendations for future interventions, in contrast to building theory (Ritchie and Spencer 1994).

More recently, it has been more widely used in medicine and health psychology research (Dovey-Pearce et al. 2007; Frost et al. 2009; Thorstensson et al. 2009)



The framework approach was chosen as the method of analysing data in this thesis this project because of its suitability to investigate *a priori* themes and ideas about health literacy from the research literature, and its suitability for identifying new themes.

The student wanted to explore if participants had practised and developed health literacy according to existing categories and models of health literacy, and discover new categories and ways of practising health literacy within different contexts. Hence, the partly deductive and partly inductive features of the framework approach were appropriate. The framework approach was developed with an aim to help address a key set of *objectives* which are key features of qualitative analysis:

- **Defining concepts**
- **Mapping the range, nature and dynamics of phenomena**
- **Creating typologies:** categorising different types of attitudes and behaviours, motivations etc.
- **Finding associations:** between experiences and attitudes, attitudes and behaviours, between circumstances and motivations, etc.
- **Seeking explanations:** explicit or implicit
- **Developing new ideas, theories and strategies.**

Below are key features of a Framework as described by (Ritchie and Spencer 1994; Ritchie et al. 2003).

**Grounded or generative** - It is heavily based in, and driven by, the original accounts and observations of the people it is about.

**Dynamic** - It is open to change, addition and amendment throughout the analytical process.

**Systematic**- It allows methodological treatment of all similar units of analysis.

**Comprehensive** - It allows a full, and not partial or selective, review of the material collected.

**Enables easy retrieval** - It allows access to and retrieval of the original textual material.

**Allows between and within-case analysis** - It enables comparisons between and associations within cases to be made.

**Accessible to others** - The analytical process, and the interpretations derived from it can be viewed and judged by people other than the primary target.

These features of framework analysis can vary depending on the research questions, and the themes that emerge from the data (continue reading to page 98 and 99 for a description of the features that were used in the current research).

The Framework approach incorporates the following five distinct and highly connected analytical *phases* (Ritchie and Spencer 1994; Ritchie et al. 2003):

- Familiarisation
- Identifying a thematic framework
- Indexing
- Charting
- Mapping and interpretation

The analysis is an iterative and rigorous procedure of moving back and forth between these phases to make decisions about how the identified themes best represent participants' accounts. Below is a description of these five analytical phases and a detailed description of how they were used for this thesis.

### **3.4.1 Familiarisation**

Familiarisation is the procedure of gaining an overview of the data; this is a necessary process that helps 'build the foundation' for the thematic framework (Ritchie et al. 2003). The familiarisation process incorporated a number of methods of generating themes. This consisted of a review : as suggested by Ritchie et al. (2003) (1) the proposal for the study, (2) the literature review, (3) interview topic guides, (4) the sample characteristics (see appendix7), (4) notes from observations and interviews, and (5) notes from transcribing and (6) themes found in the interviews.

**(1) Reviewing the proposal**

The proposal was reviewed in order to consider the research questions, the thesis, rational and the aims and objectives of the research when selecting the sections of data to include in the analysis.

**(2) Re-reading the literature review**

The literature review (chapter 2) was reviewed in order to consider current conceptualisations of health literacy and categories of health literacy and conceptual models of health literacy that have been named thus far.

**(3) Reviewing the interview topic guides**

The interview topic guides were reviewed to take into account the main areas of questioning.

**(4) Reviewing the sample characteristics**

The characteristics of the participants were taken into consideration, such as: age, condition, gender, occupation and educational attainment.

**(5) Reviewing notes from transcribing**

The notes taken by the student at the time of transcribing the data helped recapture additional thoughts and feelings about the way participants were responding in the interviews. These notes were reviewed as part of the familiarisation process.

**(6) Identifying concepts, categories and themes in the interview data**

In their method of familiarisation with interview data Ritchie et al. (2003) suggest noting down broad themes to be included in a thematic framework. However, other researchers have used qualitative software such as Atlas.ti and Nvivo to code interview transcripts prior to developing a thematic framework.

The initial familiarisation process in this thesis involved thorough inspection of the interview transcripts and a method of generating narrower concepts and categories using a qualitative software package (NVivo version 8). This process involved immersion in the data; by listening to the audio recordings of the interviews, reading and re-reading the transcripts and studying the observation notes. 'Interesting'

sections of text within the interview transcripts were assigned a code (or label) to categorise and summarise it (a process known as coding). Memos were created for some of the codes in order to explain why a particular code had been assigned to a particular piece of text and make note of potential relationships between one code and another.

There were two main reasons for the chosen method of coding into concepts and categories using a software package in the initial familiarisation stage: (1) there were a large number of interviews so coding using a qualitative software package was a way of effectively storing and organising themes, concepts and categories; (2) because of the number of differing definitions and incomplete conceptualisations of health literacy, it was necessary to undertake a close inspection of the data to identify new and extant concepts and categories associated with health literacy that could be included in the thematic framework.

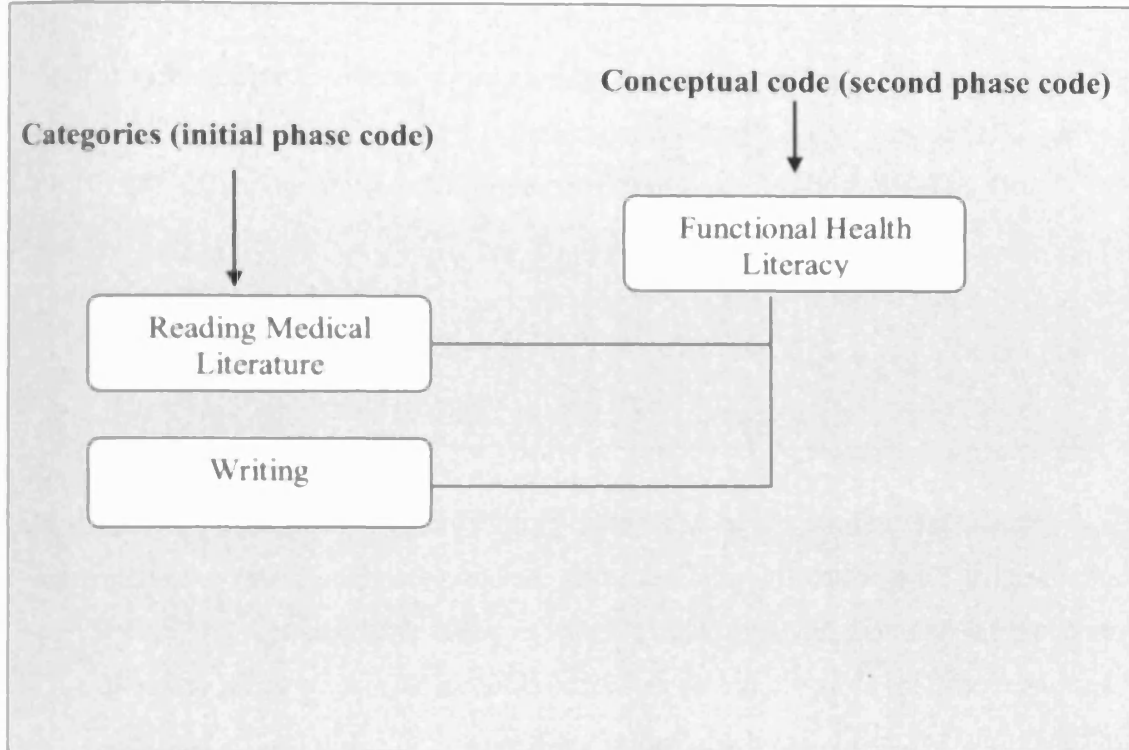
There were two phases of coding; the initial coding phase involved identifying and coding lots of small categories from the interview data. These categories can be broadly described in terms of people, events, actions, activities or practices, context, strategies, issues, attitudes, beliefs, culture, emotional responses, reflections, personal characteristics, choices and outcomes.

#### *Second phase coding (organising categories into concepts)*

The second phase of coding was developed inductively by drawing on codes from the first phase, and deductively by referring back to the research questions, aims and objectives and issues that were chosen for discussion during interviews. Firstly, the initial codes (categories) were retrieved and there was further reflection on them in relation to all other codes from the dataset as a whole. Secondly, they were refined and classified into broader conceptual codes (concepts) using NVivo8 to create a coding hierarchy. The development of coding hierarchies in this study was influenced by the methodological approach and constructs that exist within the health literacy and health communication fields. Thus, some were identified from theoretical frameworks within the literature on health literacy and other concepts were generated based on the candidate's research questions, aims and objectives and interpretations of the data. For example, all categories that related to a known construct of 'functional

health literacy' (i.e. reading books, writing) were assigned to a higher level conceptual code (or concept) called 'functional health literacy' (see figure 3.1).

*Figure 3.1 A coding hierarchy for the concept 'functional health literacy'*



This way of organising the codes into hierarchies created a 'catalogue' of concepts and categories that was useful to begin to identify patterns and relationships between them and also create an essence of what the research is about (Bazeley 2007). The construction of coding hierarchies served a number of functions (adapted from Bazeley 2007:103):

- **Organisation:** it aided the location codes. All information about a concept defined by a tree node was clearly marked in one place. The concepts were used consistently across the patient groups and interview phases so that if the same categories emerged from one group it was classified by the same concept in another group. This helped maintain consistency across the dataset and allowed comparisons to be made across all the groups.
- **Conceptual clarity:** Classifying the categories into concepts helped assign meaning to them (Dey 1993); and helped clarify associations between them. It

brought about the ability to identify common properties, identify missing categories and distinguish categories that overlapped with each other. Maintaining consistency across all the patient groups and interview phases helped bring together the whole dataset and 'tell' the project (Richards 2005).

- **Code richly:** The development of a coding hierarchy helped ensure thoroughness by enabling the identification of all relevant categories in the data set and assign them to relevant concepts within a coding hierarchy.
- **Identifying patterns:** this process aided the identification of patterns of association within participants, groups, interview phases and across groups of participants.

Organising the data into codes and coding hierarchies at the familiarisation stage helped generate and consolidate concepts and categories from across all groups and interview phases. These concepts and categories could then be reviewed for inclusion in the thematic framework which could be used as an index across the whole dataset. Approximately a third of the data were double coded and discussed with two PhD supervisors specialising in qualitative research methods. This process was aimed at achieving consistency and consensus about the main themes in the data and helped the initial development of the thematic framework.

### ***3.4.2 Constructing a thematic framework***

The coded data were used to guide the development of the thematic framework that could be used as an index to aid the systematic organisation of the whole data-set. Dovey-Pearce et al. (2007) began to develop their thematic framework after their first set of interviews and used it to guide their further data collection. In the current research, a detailed coding process guided data collection and the thematic framework was not developed until all data were collected. The first stage in constructing the framework involved reviewing all the coding hierarchies and scrutinising them for their relevance to the aims and objectives of the research questions. The second stage involved organising all relevant coding hierarchies in tables (see appendix 8), and the third stage involved grouping the coding hierarchies in further tables (see appendix 8)

under overarching themes. Thus, the updated tables now included themes, concepts and categories based on the interview data, the observation notes and theories and conceptualisations from the literature on health literacy.

The fourth and final stage of constructing the thematic framework involved transforming the tables into a first version of the thematic framework index using a Microsoft Excel spreadsheet. Each section of the thematic framework consisted of an overarching theme, a concept and then a category. For example, an overarching theme was (2) 'practices of health literacy', a concept was (2.1) 'functional health literacy', and a category was (2.1.1) 'reading medical literature and journals'.

### ***3.4.3 Indexing (applying the thematic framework to all interviews in the data-set)***

The indexing stage involved a systematic coding of all interview transcripts using a thematic framework. Indexing can be done manually by noting index numbers in the margin of a transcript or by using a qualitative software package to code sections of data against the thematic framework (Frost et al. 2009; Thorstensson et al. 2009). In the current research, indexing was carried out using NVivo8 software for the purpose of most effectively organising and storing the data.

The index was applied to the whole of the dataset. However, because the data were collected in groups and across time there were two possible ways of organising the data for indexing: by patient education group (including interview one, two and three for each person) or across time (including each interview one for every group, each interview two for every group and each interview three for all groups). A decision was made to group the interviews by their patient education group; this was because after engaging with the data during the coding processes, the context of the condition and nature of the way the education was delivered seemed to be more apparent and important to how health literacy was developed. Another reason not to index the interviews over time was that although most people were interviewed three times, some were interviewed twice (with interview one and two combined or interview two and three combined), or only once if they withdrew. Therefore, it was more difficult to assess changes over time for every participant. Although the index was not organised over time, the researcher did pay attention to changes over time and people's advancing skills and reflected on them in the final stage of analysis.

The interview data (transcripts) were imported into Nvivo8 files and grouped by their patient education groups (i.e. group one was all cardiac rehabilitation programme interviews, group two was all diabetes education programme interviews, group three all Expert Patient Programme Interviews and group four all comparison group interviews). There were four identical indexes, one for each patient group.

The interview transcripts in each group were then examined using the index; each phrase, sentence and paragraph was read in fine detail and a relevant index category was assigned to it. During this stage more categories were added to the index as the data were re-examined. Once all the data was indexed, redundant categories were eliminated and similar categories combined. Thus, a final (amended and refined) version of the thematic framework was now complete (see appendix 9).

#### **3.4.4 Charting**

The process of charting helps an analyst view the scope of the dataset as a whole and think about the range of attitudes and experiences relating to each theme or category (Ritchie and Spencer 1993). Charting is carried out by creating a set of thematic charts for each theme using a matrix format. Within each matrix, each participant is assigned a row and each sub theme is allocated a separate column. The data were charted using Microsoft Excel spreadsheets, each theme (e.g. 2. health literacy practices) was a chart heading and each concept under that theme (e.g. 2.1. functional health literacy) was used as a chart sub-heading. The categories (e.g. 2.1.1 reading medical literature) were not included as chart headings because there were too many of them and it would have made the charting very time consuming.

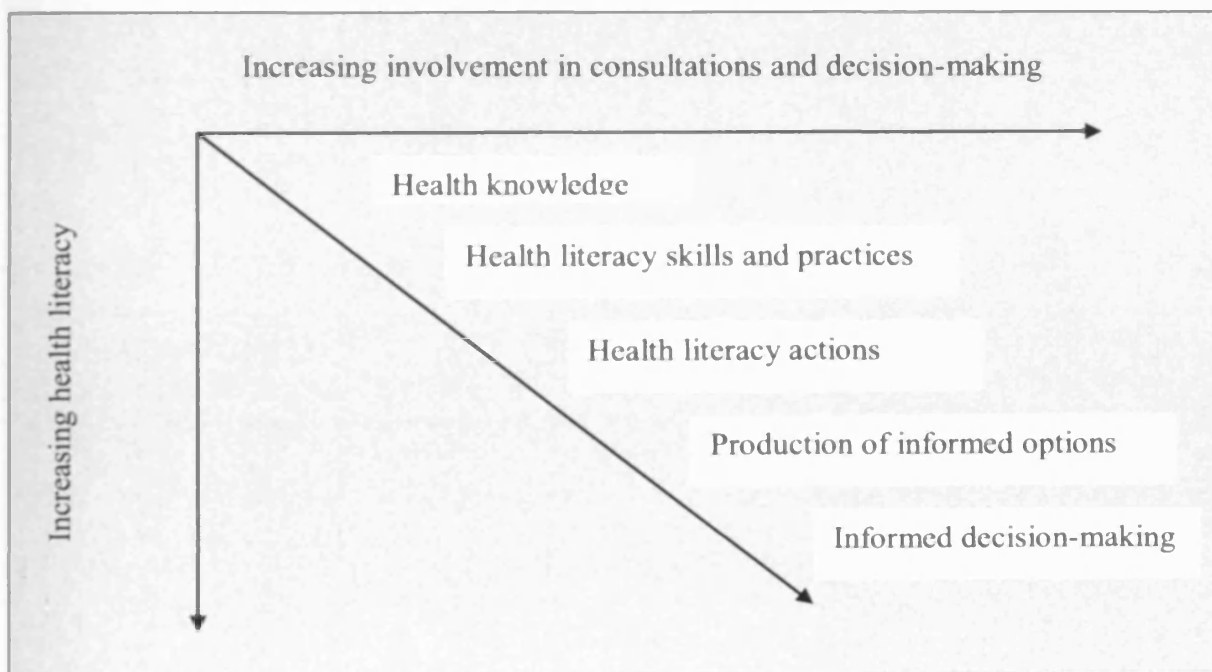
There are a number of ways that data can be entered onto the chart, including summarising or interpreting participants' comments, adding verbatim text from interviews and referencing transcript page numbers. The charting process used for this research included captions of verbatim text from interviews one, two, and three and index reference numbers (to refer back to the more detailed categories in the thematic framework). There were seven charts developed (based on the seven themes used in the thematic framework), each to be used on four groups of participants. Thus, in total there were 28 charts. (Appendix 10 presents part one of the thematic charts used in this thesis).



### 3.4.5 Mapping and interpretation

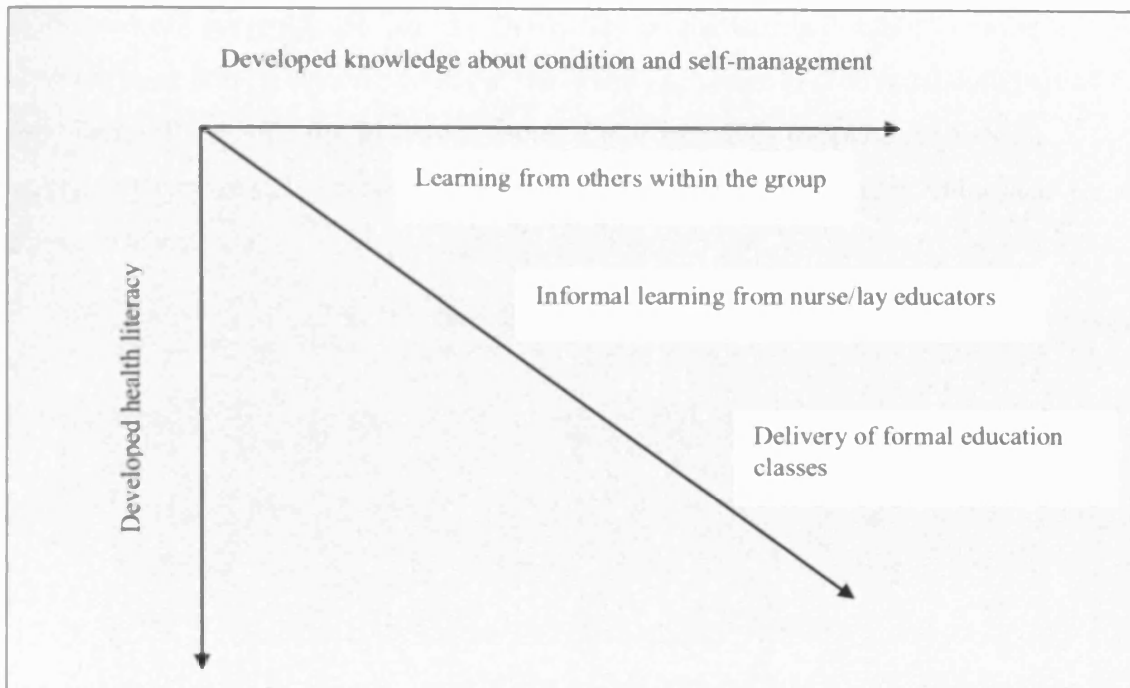
This final stage in the framework approach involved reviewing the charted data and analytical notes, comparing and contrasting participants' accounts, identifying patterns and connections in the data and seeking explanations for these within the data. These tasks helped **define new concepts** that were featured within the framework and extend the definition of extant concepts. Chapter 5 of this thesis provides the results of this analytical process in presenting conceptual developments in health literacy categories (or dimensions). Another analytical strategy used at this stage was to **create a set of typologies**. This strategy usually involves two or more dimensions that are linked at different points, providing a range of types of cases. Figure 3.2 below shows the typologies that were created to form the basis of the results presented in Chapter 6 that explain a health literacy pathway to informed decision-making.

**Figure 3.2** *Typologies of health literacy development*



A set of typologies (see figure 3.3 below) was also created in a similar way to analyse the methods of learning and health literacy development that occurred within patient education programmes (see Results, Chapter 7).

**Figure 3.3** *Typologies of health literacy development and learning methods in patient education programmes*



Other analytical strategies that were used were: **finding associations** between *attitudes, behaviours and motivations or barriers* for participants and **providing explanations** for them. Through analysing the data thus far, it was possible to use analytical ideas in a way that may help **develop strategies** for defining and measuring health literacy, further research and the development of patient education. These strategies have been suggested in the Discussion (chapter 8).

### **3.5 Chapter summary**

**This chapter has presented the rationale and procedures for the research design and recruitment. The data collection methods have been described in detail, and a step-by-step description of the method of analysis (framework approach) has provided a transparent illustration of how the data were managed and scrutinised to form a basis for the results of this thesis. Appendix 11 includes a representation of the steps used in the framework approach used for this thesis. The strengths and limitations of the methods used will be considered in the Discussion (chapter 8). The remaining part of this thesis will provide the Results. Chapter 4 will introduce the participants who agreed to take part in the current research and provide a profile of their individual characteristics.**

## **4.0 Results: Research Participants**

### **4.1 Introduction**

This chapter will describe the participants in this study. The aim of the chapter is to add an overview of the participants' personal contexts and to begin to take into consideration their personal circumstances and prior experiences that might have influenced their engagement with health information and encounters with healthcare services. Comparing and contrasting participants' health experiences and their information seeking styles in the final stage of the framework approach helped form a profile for each participant (for a summary of the participants demographic details please see appendix 7).

### **4.2 Cardiac Rehabilitation participants**

#### ***Participant 1CR***

Participant 1CR was a 76 year old female who lived with a male partner; she was a retired cashier who had previously worked for a national pharmacy retailer for almost 30 years; her educational attainment was high school level. She reported no experience of hospitalisation during her life and no previous health concerns apart from a duodenal ulcer. Although there was a history of heart disease in her family, it was with males and she had not related their experiences to her own risk of developing heart disease. She experienced a heart attack whilst in hospital for surgery for a hip alignment. She had by-pass surgery which was a great shock and surprise to her. She attended the education classes and exercise classes twice weekly. She was not computer literate and held firm beliefs that she should not seek any other information and should listen to her doctor for all information and advice about her health. Her beliefs were based on advice given over 20 years ago that she must not read health books or leaflets and to always ask the doctor (this was suggested to her by her employers). She was compliant to advice given by health professionals and was happy to adhere to medication regimes without question.

*Participant 2CR*

Participant 2CR was a 77 year old married male, he was a retired insurance broker and level of educational attainment was high school. He had by-pass surgery after experiencing angina and has experienced a few health problems such as diabetes and asthma. His wife organised his regime every day, he also had three daughters who took an interest in his health. One of his daughters was a radiographer and she knew the surgeon who operated on her father and had telephone conversations with him about her father's condition. Participant 2CR claimed that his daughters knew more about his surgery and condition than he did and he joked that they were like a 'secret society'. He did not use a computer to seek information, but his daughter looked up some information online and printed it out for him. His daughters and his wife appeared to be more informed than him about his health conditions and how to manage them. He had problems remembering correct names for his medications during the interview and conveying information about surgical procedures.

*Participant 3CR*

Participant 3CR was a 77 year old widowed female; she had a long term management position with a cosmetic firm before more recently retiring from a position as a receptionist in a private hospital. She was privately educated to 'A' Level standard at a prestigious school for girls and has private medical care. She had heart surgery and attended both education and exercise classes provided by the cardiac rehabilitation team. She was not computer literate enough to seek information online but her daughter would seek information online and share it with her. She was compliant to advice offered by health professionals and was happy to adhere to a medication regime. She had problems remembering names of medications but was happy that she knew why she had to take her medications and followed medication advice offered by her GP.

*Participant 4CR*

**Participant 4CR** was a 23 year old junior physiotherapist. She was therefore university educated in a health profession and had an advanced knowledge of health and medical terms. She was unable to work at the time of interview one and two and had returned to work part time by the time of interview three. She lived in an apartment with her boyfriend. Her parents live about a two hour drive away in another city. She was diagnosed with an extremely rare heart condition (she is one of only four people in the UK who has had the condition and only she and another person are still alive). She has private healthcare and has been hospitalised in the local city hospital and also sent to London for more specialist investigations. She has contact with multiple healthcare specialists in both her resident city and in London. She has a number of symptoms to manage and takes a number of medications including steroids, warfarin, hormone tablets and iron tablets. She has regular tests in London and her resident city and after having her INR monitored by healthcare professionals she now monitors it herself. She has more advanced skills in accessing health information and is familiar with medical terms and research papers; she also has access to the advice of other health professionals at work. She chose to take part in the exercises classes run the by the cardiac rehabilitation team but not the educational classes.

*Participant 5CR*

**Participant 5CR** was a 54 year old male; he was university educated and worked from home as a draughtsman. He lived with his wife and children. He had heart by-pass surgery and attended both the educational classes and exercise classes run by the cardiac rehabilitation team. He was computer literate and searched for health information online. He considered himself to be informed about his condition and discussed what he knew about it in consultations with his GP.

### ***4.3 X-PERT Diabetes Programme participants***

#### ***Participant 1XP***

Participant 1XP was a 72 year old male; he was a retired vending machine engineer and was high school educated. He lived with his wife and has had heart disease in addition to diabetes. He worked for a few hours doing gardening jobs for a local GP during his retirement and had talked about his health concerns with him on several occasions. He does not use a computer to look for health information but watches health programmes on television and reads health related articles in the press. He was a member of Diabetes UK and attends meetings and receives a regular magazine from them.

#### ***Participant 2XP***

Participant 2XP was a 53 year old female, who had been a housewife most of her adult life. She had high school level education. Her husband previously owned a successful business and they live off the money from the sale of the business. She had a disability and has to manage pain in her legs in addition to her diabetes. She had diabetes for thirty years and is an organising member of Diabetes UK. She attended meetings and held regular fundraising events at her home and collected donations and raised awareness of diabetes within her community. Her husband attended the programme with her, although he is not diabetic. She had access to health information through Diabetes UK but did not have computer skills to search online; her husband looked up information for her and printed it out for her to read.

#### ***Participant 3XP***

Participant 3XP was a 52 year old female; she worked part-time as a learning support worker with mothers and young children. She was newly diagnosed with diabetes at the start of the programme and had not been given much information on diabetes from her GP surgery. She used a computer and bought books to become informed about diabetes, she also became a member of Diabetes UK after talking to participant 2XP. She had several frustrations with the service at her GP surgery

*Participant 4XP*

**Participant 4XP** was a 70 year old female; she was a semi-retired bank worker and worked part time as a club secretary. She had recently been diagnosed with diabetes after a routine blood test. She was asymptomatic and had never experienced any ill effects associated with diabetes. Both she and her husband both looked online for information about diabetes. However, she found it difficult to accept and come to terms with her diabetes and rarely disclosed it to anybody because perceived social stigma to be attached to diabetes. She had a history of diabetes in her family, her grandmother and her aunt had diabetes and both suffered with severe effects. Although she had no memory of how they suffered, quite graphic details of their suffering were passed down in family stories. She was fearful that she could suffer in the same way in the future.

***4.4 Expert Patient Programme participants***

*Participant 1EP*

**Participant 1EP** was a 50 year old female who suffered with epilepsy and osteoarthritis, she lived alone and suffered from a lot of pain and is partly disabled. She previously worked as a cook but her current health condition prevented her from working. She was previously seriously ill with meningitis and had spent a lot of time in hospital and had numerous consultations with health professionals for most of her adult life. She was unable to use a computer because she has epilepsy and it was not safe for her to read from a computer screen. She had a medical reference book and seeks written health information provided in leaflet form.

*Participant 2EP*

**Participant 2EP** was a 46 year old male who had bi-polar disorder since his early twenties. His occupation was a construction worker but he was unable to work because of his condition; he was also completing a university course before he became unwell with depression and was hoping to return to it when he felt better. Before joining the programme he had been feeling depressed and was adjusting to a higher dose in medication. He used a computer to research psychological therapies and treatments and also to read about experiences of other people. He had read a number of self help books and was aware of different forms of treatments. He had



regular contact with a GP and a psychologist. At the time of the study he lived with his brother who also had a mental illness (schizophrenia).

*Participant 3EP*

Participant 3EP was a 49 year old female; she suffered from a condition that affected her shoulder. She also had a 14 year old daughter with a serious health condition; her daughter suffered with a lung condition, diabetes, curvature of the spine, learning difficulties and a heart condition. Participant 3 EP lived with her daughter and a son. She is from an African country and sought asylum in the UK with her children. She is college educated in her own country and was previously a teacher. She had not worked since she came to the UK and took care of her daughter full-time. When her daughter is at a special school she takes English courses and computer courses. She did not use a computer for health information; her main source of information was from health professionals. She had regular contact with a number of specialists who see her daughter at the hospital. However, she did sometimes struggle to understand all the information that is provided to her because of her English language difficulties.

*Participant 4EP*

Participant 4EP was a 66 year old retired lecturer and dietician/nutritionist, and had bipolar disorder. She had been diagnosed for over twenty years and had previously spent time in hospital under a section. She had an interest in complementary and alternative treatments and had tried out some of them. She did not seek health information online because she was not skilled in computer use; her husband looked up information online and printed it for her. She was well informed about bipolar disorder, wrote to a number of health organisations for information, and participated in a bipolar research programme and received information from them. She also had osteopenia and looked for specific and related information on that.

*Participant 5 EP*

Participant 5EP was a 31 year old female; she had been diagnosed with a rare brain disease known as Acute Disseminated Encephalomyelitis (ADEM) for a year. She had a wide range of symptoms and disabilities that were similar to those experienced in Multiple Sclerosis (MS). She had nerve damage which caused her to be in pain and experience problems walking about; she also got frequent bladder infections and was visited by a nurse to help with them. She suffered from seizures and short-term memory loss and was at risk for further seizures. There was uncertainty about her prognosis as her disease was very rare. Although her symptoms were similar to MS, she had been unable to access similar healthcare services as people with MS. She lived alone and her mum visited most days to assist her at home. She was college educated and had worked as a healthcare assistant in the NHS and more recently in a social care and housing role. At the time of the interviews she was unable to return to work but had hoped that she would be able to in the future. She had difficulties finding sufficient information about her condition from health services so she and her family looked up information online. Because her symptoms were similar to MS she tended to read a lot about that and apply that information to herself.

***4.5 Comparison group participants***

*Participant 1C*

Participant 1C was a 60 year old male; he previously had by-pass surgery for symptoms of angina. He attained university level education and was a semi-retired secondary school teacher. He responded to an advertisement for participants at an adult education centre. He was a tutor at the centre and taught courses in household plumbing and home improvement. He looked for health information online and had participated in some health screening research projects. Although he took several medications such as beta-blockers and statins, he did not feel that he had a current or long-term medical condition that needed to be managed. He had not participated in a phase three cardiac rehabilitation programme and returned to his usual exercise regime shortly after his surgery. He had strong ideas about what his blood pressure and heart rate should be and disagreed with the medication dosages that his GP had given him and makes his own decisions about whether he will take his medication or not. Therefore, he was resistant to some of the medical advice he has been given and at times did not adhere to his prescribed medication regime.

*Participant 2C*

Participant 2C was a 42 year old female diagnosed with borderline personality disorder; she lived with her husband and is not in employment. She was college educated and had a career in the army when she was younger. She completed a number of courses at her local adult education centre (e.g. psychology and computer skills). She was given details of the study by the centre manager, who knew her well and knew that she had a long term condition. She read the information and sent in a consent form to agree to participate in the study. She accessed online information about her condition and both medical and psychological treatments. She had visits from a community psychiatric nurse and a social worker and attended a day service and a mental health charity group. She also received advice and support from friends with the same and similar condition to her. However, she did sometimes find it unhelpful to be around other people who were feeling depressed.

*Participant 3C*

Participant 3C was a 46 year old male who experienced chronic back pain due to a trapped nerve and 2 slipped discs. He was married with children and had worked as a hospital cleaner before being unable to work due to his condition. He was from Madeira and has attained a high school level education. His wife found out about the study because she worked at the community education centre and she passed some information on to him. He then returned a consent form and was included in the research. He did not seek information on his condition from elsewhere and relied on the information that he was able to obtain from health services. However, his first language was Portuguese and he had some problems understanding information that was communicated to him in health consultations. He also felt that some health professionals had not made an effort to communicate information to him, especially where procedures are concerned.

*Participant 4C*

Participant 4C was a 45 year old female who has suffered from chronic asthma and allergies since childhood. She was married with children and was a manager in social care and was university educated. This participant was a personal contact known to the student and had agreed to take part in the research. She was eligible to participate

in the research because she had been living with a long term condition but had never participated in a patient education programme. She took regular medication to prevent symptoms and had been hospitalised a number of times. She looked up information about her condition and also received some information from Asthma UK. She was also interested in alternative and complementary therapies and had tried them to treat her asthma in the past.

#### **4.6 Chapter summary**

This chapter has introduced the participants and put into context some of their personal details and information seeking styles. Most participants had a physical health condition and three had a mental health condition; those with a mental health condition appeared to be well informed about their condition and were aware of potential treatments and services but were sometimes unable to access these services. The two youngest participants (4CR and 5EP) had rare conditions and less information was available to them, both their conditions were serious and there was uncertainty about their prognosis.

Some were more reliant on information provided by health professionals and tended to be compliant (for example, 1CR, 2CR, 3CR and 1 EP) and others were better informed and actively sought further information independently (for example, 4CR, 2XP, 4EP, 5EP, 2C and 4C). Others struggled with language barriers (3EP and 3C), whilst others had worked in the health profession or had a health-related educational background so understood medical terminology better (4CR, 4EP and 5EP). Most participants had access to a computer or knew someone who could access information for them. Those who did not, used other methods such as referring to books and leaflets or writing to health organisations. Older participants were less likely to be computer literate (1CR, 2CR, 3CR and 4EP) whereas younger participants (4CR and 5EP) had high level computer skills and accessed more complex medical information. Although there was a range in educational attainment, this did not appear to influence information seeking. It may be likely that age or factors related to the duration and seriousness of the condition were more of an influence.

Some participants had access to support groups and received support from families and friends, whilst others were more independent due to reasons related to their

acceptance or disclosure of their condition (4XP) or to their information preferences (1C, 1EP, 2EP). Three of the patients with diabetes had joined Diabetes UK and had attended meetings and received their monthly magazine. Some participants also accessed information and support from other health organisations.

Most of the participants were compliant to medical advice. However some were interested in alternative herbal treatments (4EP and 4C) and one other had strong ideas about his treatment regime that were different to those of his GP (1C).

The details provided here help build a profile of each participant that can be related to interpretations of their experiences throughout this thesis. Therefore, the results from this chapter will be referred to and explored further within a framework of 'health literacy' from here on. The next chapter will introduce the themes that emerged from data analysis and describe a 'health literacy framework' that was created from engagement with the health literacy literature and participants' interview responses.

### ***Overview of thematic framework and introduction to empirical findings***

The remaining part of the thesis will present empirical results based on the analysis and interpretation of participants' responses and observations of patient education classes. The framework approach (Ritchie and Spencer 1994) was used to analyse the interviews and observation notes in this thesis included themes derived from the literature on health literacy and new themes that emerged during familiarisation and engagement with the data. Seven overarching themes were identified. These were:

#### ***Health literacy practices and categories***

Subthemes incorporated into this theme were categories of health literacy that were defined within the literature and identified through familiarisation of the data. These were created by grouping health literacy practices into categories. The themes are as follows: *functional* (e.g. reading, writing), *interpersonal* (e.g. discussions with professionals, communicating preferences), *critical* (knowledge of rights, accessing medical notes), *scientific* (e.g. biological knowledge, research interest), *interactive media* (e.g. searching online, social media), *civic* (e.g. concern about the rights of others), *risk* (e.g. environment, family), *distributed* (e.g. family/friends support), *food* (e.g. understanding food labels), and *cultural* (e.g. culturally relevant information).

#### ***Motivation and barriers to health literacy***

Subthemes incorporated in this theme included factors that motivated participants to seek and engage with health information (e.g. reduce fear, make sense of symptoms), barriers (e.g. compliance, attitude towards information seeking), and factors that were important for participants to know (e.g. procedures, medications).

#### ***Accessing Needs (information and care services)***

Subthemes incorporated in this theme were about *accessing services* (e.g. asking for specific services), *accessing advice* (from family or health professional), *accessing needs* (e.g. equipment, results, medication), *system barriers to access* (e.g. limited information available), *health professional barriers* (e.g. poor communication), *health professional facilitators* (e.g. interest/knowledge of patient) and *personal barriers* (e.g. poor acceptance, conflict).

***Self-management***

Subthemes were: *medication knowledge* (e.g. effects, options), *managing medication* (e.g. dosages, changes), *knowledge of the body* (e.g. symptom awareness), *self-care* (e.g. self-monitoring), *keeping records* (e.g. medications, results), and *managing people* (e.g. multiple health professionals).

***Psychological Impact***

Subthemes were: *emotion* (e.g. fear, shock), *readiness* (e.g. acceptance), *reflection* (e.g. lifestyle, health, decisions), *life* (e.g. moving on), *support* (family, group), and *adjustments* (e.g. activities, lifestyle, career).

***Decision Making***

Subthemes were: *decision making* (e.g. desire for involvement, presentation, support), *barriers* (e.g. confusion), *choices* (e.g. seeking), *compliance* (e.g. trust, acceptance), *influences* (e.g. family, internet), and *exchanging information* (e.g. results, medications).

***Learning***

Subthemes were: *making changes* (e.g. food, exercise), *learning* (e.g. self-directed, education), and *developments over time* (e.g. come to terms).

These seven themes and their sub themes were used as a framework to analyse the data and define new concepts, create typologies, find associations, provide explanations and develop strategies for defining and measuring health literacy (see chapter 3). Chapter five will introduce the initial results describing health literacy categories, chapter six will introduce a model of how health literacy develops along a pathway, and chapter seven will describe the ways that participants might become more health literate through patient education. The complete framework is presented in appendix 9.

## 5. 0 Results: Evidence-based health literacy categories

### 5.1 Introduction

This chapter will answer the following research questions: (1) *what is “health literacy”* (2) *how is it practised in different health contexts (situations and activities relating to health)?* The aim of the chapter is to contribute to current categories of health literacy and provide a range of health literacy categories that can guide the development of more comprehensive health literacy assessment tools than are presently used in research and practice. Themes from interviews with participants are interpreted and organised to provide evidence for a set of health literacy categories (or dimensions). Some of these categories are extended descriptions of categories currently described in the health literacy literature (see chapter two – Literature Review) and some have been created from this research based on participants’ accounts of how they sought, engaged with, and used health information to manage their condition. There were eleven categories of health literacy identified:

- **Functional health literacy:** is a widely recognised dimension of health literacy that involves reading printed material and writing. Skills in this category form a basis for skills in other health literacy categories.
- **Scientific literacy:** is a dimension that has featured in Zarcadoolas et al.’s (2003; 2006) conceptualisation of health literacy. Here it has been *extended* to feature an understanding of scientific processes, biological processes, medical language, understanding and engagement with research evidence.
- **Health risk literacy:** is a *new* category of health literacy that has been described from the findings in the current research. It refers to an understanding and awareness of risk factors for a health condition, awareness of environmental and lifestyle risks and medication risks.
- **Food literacy:** is a *new* category of health literacy that relates to an understanding of food labels and nutritional information, and an understanding of how food can affect one’s health in terms of risks and benefits.
- **Interpersonal health literacy:** is a *new* category of health literacy that extends aspects of Nutbeam’s ‘interactive health literacy’. It relates to oral communication with another person about one’s health and developing interpersonal relationships within health contexts.



- **Interactive media literacy:** is a *new* category of health literacy that is partly inspired by interactive health literacy (Nutbeam 2000b). It is focussed only on interaction with online media sources and relates to engaging with online information sources, social media, online discussions and message boards.
- **Critical health literacy:** is a category introduced by Nutbeam (2000), it relates to critical analysis of information to support social, political and individual action.
- **Civic literacy:** is described in relation to health literacy by Zarcadoolas et al. (2006; 2003). It involves an understanding the connection between citizenship and health.
- **Public health literacy:** is described by Freedman et al. (2009) and refers to the ability to understand and evaluate public health information.
- **Cultural literacy:** is a health literacy domain recognised by Zarcadoolas et al. (2006, p224) and refers to “the ability to recognise and use collective beliefs, customs, world view, and social identity in order to interpret and act on health information”.
- **Distributed health literacy:** is a *new* category of health literacy that has been developed in this thesis to describe how people draw on the health literacy of other people within one’s family, social or professional network as a personal resource.

Health literacy categories were not always practised in isolation; they were often interconnected and used in combination. Throughout this chapter these categories and relationships between them will be described and exemplified with data extracts.

## **5.2 Functional health literacy**

Functional health literacy is described in current literature mostly in terms of literacy skills that are practised within a range of health contexts (situations and activities relating to health). Functional health literacy according to Parker et al. (1995) represents the ability to '*apply literacy skills to health related materials such as prescriptions, appointment cards, medicine labels, and directions for home health care*'. Functional health literacy in this thesis represents basic abilities associated with reading, numerical understanding and writing that facilitate an understanding of health in general, one's own health concerns (including risks) and the management of health and use of health services. This section will explain how participants demonstrated some of their functional health literacy abilities in their engagement with written materials (including books, newspapers and medication leaflets), written work and numerical understanding.

### **Reading written information**

Functional health literacy was practised by engagement with written health information resources. Some had medical reference books and books relating to their condition and referred to them either instead of searching online or to help them understand medical terms that came up in online searches. Here two participants from the expert patient group talk about how they used medical books:

I'll refer to the medical book um I don't know if that's a good thing or a bad thing but some people swear by it and you must look at this and think I'll fight this problem, stop talking to the doctors you know...I'm not one of those it's just I like to know what's going on with my body. (Participant 1EP)

I've got a really good medical dictionary and I also find some of the sites, they underline something they kind of explain. I think it's .... I'm not sure if it's patient.... Or is it net doctor maybe that's quite good. I've come across quite a few of them that were explained or I just get my dictionary out and have a look. (Participant 5EP)

Some participants who suffered with depression had read self-help books and books about experiences of depression to help them understand their condition and cope with or manage it better.

Some of the things they are telling me I already know about through looking at self help books over the years. (Participant 1EP)

Some participants with diabetes owned diabetes recipe books and books about carbohydrates and received a regular magazine from their subscription to Diabetes UK. Some participants read newspaper articles about health issues in newspapers, some had read about current health issues such as swine flu and others paid attention to specific information regarding their own health condition and medications that they were taking. Some made sense of the side effects that they had experienced and found out more about potential side effects of medications that they had been prescribed; they made decisions about taking them based on the information.

After I'd had a heart attack and it had given me a cough so I went to the doctors and I read in the paper one Sunday, somebody was writing in about side effects for tablets and it said you are taking a tablet with 'pril' on the end you will have a cough. (Participant 1XP)

Yesterday I read that aspirin is a help against cancer, bowel cancer and I thought that's good but I also read many years ago that aspirin causes internal bleeding and that always stuck in my mind so instead of taking an aspirin every day I take it every other day, you know and that's my choice that is you know. (Participant 4XP)

Participants were asked about whether they read through information that came with their medication. There was a mixed response, some did read and understand the information on potential side effects, some chose not to read the information and to just follow instructions given by their doctor and some appeared to understand the gist of information but could not remember it verbatim. Those who chose not to engage with medication information appeared to be more compliant and trusted the advice of their doctor as definitive. Some participants said that they failed to remember the names of some of their medications and mispronounced some others. Those who had problems with medication names were usually elderly participants (over 70 years of age). One participant (2CR) describes below how she is not good at remembering the names of medications, although she did mention in one interview that she understood why she had to take them and how many she had to take:

Um I'm not very good at remembering names of the tablets I'm taking. I know why I'm taking them but you know some women know it all don't they. I'm not very good at that. (Participant 2CR)

Participant 2CR also had problems remembering the names of his medications and gave vague accounts of tests he had received and surgical procedures that he'd had. Although he had a vague understanding of his investigations and treatment, a lot of the information that he recounted in his interview was confused.

I take half a yellow pill at night and a pink one which is cholesterol I think and then I take four statins, is that the diabetic one? (Participant 2CR)

His understanding of the electrocardiogram (ECG) tests that he had were constructed in terms of 'calibration' (see excerpt below). He seemed to have had some idea about what was being done but misused terms.

...I did go to the doctor because this was a pretty tight band see so that's what started it off. They did all the calibration and all that and you know...you know when they put all these calibrators on you and look into the monitor and its going boomp boomp and all that.... (participant 2CR)

Participant 1XP often forgot the name of medical terms during his interviews and sometimes mispronounced the names of his medications. He mispronounced the names of medications such as simvastatin and gliclazide and had problems remembering the word 'chiropodist'. He often replaced words that he could not pronounce or had forgotten with 'wossiname'. Below is an example of this from an interview:

Well the only thing I did have and I do read it but it bothers me a little bit is the Metformin. That was the one that I wondered well why... what is this for and I really haven't read the pamphlet inside thoroughly. I only go straight to the side effects, if I was to read it from one to twenty or whatever I'd read in there what the tablet was given to me for. I take it to help with the bloody wossiname (diabetes) because my wossiname (pancreas) isn't making enough insulin isn't it? (participant 1XP)

The previous excerpt shows that although he had difficulty remembering words, he may have had some idea what his medication was for and how it worked. However, it is difficult to interpret from this statement whether he fully understood or just could simply not remember the names.

#### *Understanding numerical information*

Numerical understanding is one dimension of a concept described as “health numeracy”. Health numeracy is defined by Golbeck et al., (2005, p375) as

“the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions.”

Health numeracy was not explored in this study, however, the understanding of numerical information is usually incorporated into definitions of functional health literacy and has been done so in this study. There was not much talk about numerical understanding in the interviews. There was only one response that gave an indication of numerical understanding. Participant 1XP talked about risks of side effects associated with an inhaler that he had been prescribed for a chest complaint. It appeared that he had misinterpreted the numerical information, which would then give him an incorrect assumption of his own risk of experiencing that particular side effect. However, his statement is an interpretation of what he had read so it is difficult to judge whether he did understand the information at the time he read it or whether he had difficulty in remembering the information when recounting it in an interview.

I read the do's and don'ts and the slip inside back to front. Because I was reading one day and there were 32 to the particular tablets she had given me. I wasn't going to have 32 of them I wasn't going to have one, but they were bloody there. And I had this pump yesterday and I thought before I start using it I'm going to get the leaflet out of the box and it is surprising what goes on with that. It's telling you what it can give you and mine is, fairplay mine has got 1 in 1,000, 1 in 10,000,000 you know... won't have this. But it's 1 in 1,000 will get it and I thought well I might be the 99<sup>th</sup>. (participant 1XP)

*Writing and organisation of written information*

Some participants kept written records of their symptoms and wrote lists of questions to prepare for consultations. Some filed all their correspondence with health professionals and kept files of information leaflets and newspaper articles regarding one or more condition that they had. Participant 4CR kept a journal of her appointments and noted down her symptoms to prepare questions to take to consultations. Participant 4EP also wrote down information about her health to prepare for consultations. Below are extracts from interviews where they both talked about making notes and keeping records.

It's a huge ability to organise, I have only now got to the point where I don't really have to think about it I know because I can retain information now but I know that I have got two appointments next week for different things, one with my GP, one here and I've got two at the end of this month over one weekend one on Friday one on Monday and that's my round with everyone seen once again for this month. I've got lists, I used to have lists of things with questions that I need to ask next time I see them ask them. I record things that have happened so if I had lots and lots of palpitations or something I tend to be quite loud in the mornings so my tick quieters down in the afternoon and things like that.

(Participant 4CR)

I always prepare questions before I go. I have a notebook I use for medical consultations and I prepare information for him about my mental health and about my physical health and to discuss with him the medication that I'm on and whether it can be reduced. (Participant 4EP)

Participant 4EP wrote a letter to her psychiatrist on one occasion and mailed it to him ahead of a consultation. He had asked her to let him know if she felt any effects from reducing her Lithium medication and she had written her ideas in her letter to prepare for further discussion in her upcoming consultation. However, much to her disappointment, the discussion did not happen. Below is an extract where she talked about this:

I'm on lithium and he reduced me from 600mg to 400mg a day and he asked me to let him know what the effect from reduced Lithium dose was. So I wrote him quite a detailed letter on what I thought the significance was but it had virtually no effect either negative or positive and I attached to it a list of all the other medications and the supplements I was taking and sent it to him so he had it in good time before the next consultation, but he just didn't really acknowledge that I'd given him much information at all. (Participant 4EP)

Most of the participants who did not use or have access to a computer wrote to various health organisations requesting information. Both participant 4EP and 3EP had written to a number of organisations to request further information on conditions that they had. Both participant 1XP and participant 4EP responded to newspaper advertisements offering information on their condition.

### ***5.3 Scientific literacy***

Zarcadoolas et al., (2003) describe scientific literacy in terms of understanding the science behind health and health improvement. In this study scientific literacy represents the understanding of scientific and medical language, biological processes underlying health conditions and health improvement and an understanding of health-related research. This dimension of health literacy is heavily based in knowledge and understanding of factual information and analytical skills. Some participants had a good knowledge of biology and health prior to developing a long-term condition and were able to learn a significant amount of information about their condition over a short space of time. For example, three participants (4EP, 4CR and 5EP) had health related educational qualifications and had been employed within health education, health services and social care. All three had a good vocabulary of medical terminology and a detailed understanding of the effects of their condition and how their medication acted in their bodies. They knew how to access research reports and owned or had access to medical reference books. Participant 4CR (a physiotherapist) and participant 5EP (a social care worker) had the most complex set of symptoms, both were on a number of medications and there was uncertainty about the long-term effects of their condition. There was a lot for them to learn in terms of understanding their condition and managing their medications and symptoms. Below are extracts from their interviews where they described their understanding of the biological processes that were involved in their symptoms:

I had vasculitis so the walls of my aorta became destroyed and they expanded and the disease progressed down to my valve and expanded and ate my valve so they had to replace the whole lot and that's why I didn't have blood pressure so I was fainting and dizzy and didn't have exercise tolerance.  
(Participant 4CR)

I've had multiple MRIs, CT scans, PET scans and lots more histological tests and so it's a rare condition and I'm the 4th person in the UK. They have three other living.... no two other living people at the moment that have it. Um just like arthritis just like vasculitis but specifically affects the ascending aorta. So it doesn't go beyond the arch or the descending area that just goes up to the brain. Hopefully it will stop there so there's a little bit left because they didn't take all of my ascending aorta out so there is a little bit left which is still diseased which is why I'm on the drugs and I have to stay on them so I'm on immune suppressors to stop my immune system eating myself. (Participant 4CR)

..... it's to do with acute deterioration of your myelin sheath basically and with all this being attached to your nervous system is all being attacked and your body um..... (Participant 5EP)

Other participants who had not had a health or medical related education also had some understandings of biological causes and processes involved with their condition. Participant 2EP had some understanding of chemical imbalances that are associated with depression. He used this understanding to make sense of his own depression and the effect that physical activity had on his mood. Before becoming too ill to work he had a very physical job and in his interview he had explained that he often overworked when he was feeling low and would eventually wear himself out. He thought the reason that he wanted to work so much was associated with lifting his mood, which raised his serotonin level and made him feel better. Below is an extract where he talked about serotonin:

.....I understand about the synapses I've read stuff about that and the lack of serotonin so it can't reach the um uh the synapse and that walking and physical activity um release serotonin which is sort of opposite to depression. It sort of lifts you which with my job I can understand why I it goes up all the time I've got a physical job I'm a carpenter builder so it was all physical stuff. So I could understand why working, not that I understood it at the time but looking back that's what I was doing. (Participant 2EP)

Participant 2XP had an understanding of the biological factors associated with diabetes and the effect of drug medication versus injecting insulin on her body. She did not like the side effects from oral medications and felt injecting insulin was treating her better and reducing side effects. Her understanding of how the medications acted in her body helped her evaluate ways to treat her diabetes and make informed decisions about which treatment would minimise side effects and work best for her. Below is an extract where she talked about the benefits of injecting insulin:



.....because my insulin naturally isn't working for me or I haven't got enough or it whatever the thing is. By giving myself what I'm missing which is natural insulin I haven't got the side effects.  
(Participant 2XP)

Most participants checked their understanding with a health professional and discussed the implications of making any changes to their medications and seemed to share their knowledge and decisions with a health professional. However, participant 1C seemed to have his own understanding of the biological processes involved with his heart condition and was sometimes reluctant to follow medical advice on offer. He seemed to prioritise his own knowledge of his body when making decisions about treatment. For example, he felt that he knew enough about how his heart worked to make an independent decision to withdraw from taking beta-blockers for the period of a month to monitor the effect on his heart rate. See below:

.....when I would walk uphill I would walk along very quickly and then my limbs would become tired. The reason they are becoming tired is because the heart isn't pumping enough blood to go through the lungs, so the lungs have to oxygenate the blood. Consequently the muscles aren't getting rid of the build up or they are not getting sufficient oxygen to get them working again. They are working anaerobically, they are not working aerobically, and the net result is you tire more quickly so I have stopped taking the... my maximum heart rate is just over a hundred whereas when I was exercising previously it was 135/140. Um, I've stopped taking the beta blockers for a period of a month and my heart rate went back up to 120/130 and my legs weren't getting tired because my heart was working more effectively, the lungs were getting more oxygen. Consequently everything works better. Why am I on beta blockers? Basically it's a doctor being perhaps over careful or over cautious.  
(Participant 1CR)

### *Engagement with research*

Scientific literacy skills that were associated with engaging with research were the ability to evaluate and analyse research results and make decisions about potential drug treatments. Some participants were interested in new drugs and had some understanding about drug trials. Some were critical of research and appraised sources in terms of whether their results were objective enough. For example, participant 4C talked about her scepticism about the reliability of research information provided by pharmaceutical companies and explained that she considered research that was carried out by a university to be more objective.

If it's the companies themselves I'm slightly more sceptical than if it's sort of research done by universities about... you know a study of it and some of the findings and things, I feel a bit more reassured by that. Whether that's right or wrong I don't know but it seems a bit more objective so hopefully it's a bit more reliable but I do take the pharmaceutical trials and studies with a bit more um scepticism. (Participant 4C)

Some wanted to know about the results of research carried out on newer drugs before trying them out. Participant 1 EP was interested in whether new drugs that were offered to her had been used in trials and how effective they were before making a decision about taking up the treatment. She was analytical when thinking about the results and what they might mean to her.

How long does it take for the medicine to work, basically? And is it going to work and have they done trials on them? Obviously they have done trials but have they tested it you know have they taken a mean average like how many people it's worked on? Say for instance I'm not going to start popping anything in my mouth. (Participant 1EP)

Participant 4CR had extensively researched information about her condition and the drugs she was taking. She was aware of new drugs that were being tested and had read about a drug trial that she would like take part in, she had read about how the drug worked and after evaluating the research she felt that it may be suitable for her and she wanted to ask her consultant about the trial.

Yes, there's a really exciting one at the moment. I don't know if I'm meant to know but I do know that my cardiologist is running it so next time I see him I'm going to tackle him about it. It's a very exciting new drug that replaces Warfarin. So at the moment I'm doing 6.5mg, the next day I've got to take 7 depending on what I eat. At the moment it tends to be quite steady but my INR still fluctuates, my level, whereas on this drug I would take one pill a day and it does the same as long as my INR is fine.  
(Participant 4CR)

#### 5.4 Health risk literacy

Health literacy is important to understanding, interpreting and evaluating qualitative risk information (i.e. risk information that is not presented in numerical or statistical form) and quantitative risk information (i.e. numerical, quantitative, graphical, biostatistical and probabilistic health risk information). In this thesis “health risk literacy” represents the understanding of both *qualitative* and *quantitative* health risk information and the ability to evaluate it and apply it to one's own circumstances, and the capacity to make relevant changes to manage one's risk. Health risk literacy was related to understanding risk related information that came from: (1) written information such as websites, medication information in books, magazines, leaflets and booklets, and (2) information that was verbally communicated through interactions with health professionals or from personal accounts given by friends and family. Health risk literacy was sometimes facilitated by functional, interpersonal, interactive media and scientific health literacy skills. During interviews participants reflected on risks that may have been present before they developed a condition (such as genetic risks, behavioural risks, environmental risks), risks associated with invasive medical procedures that they had undergone (e.g. angiogram, bypass surgery), and potential risks associated with their condition such as medication risks (e.g. side effects, overdosing), environmental and occupational risks and lifestyle risks (e.g. associated with leisure activities and travel).

### *Perceptions of risk*

Most participants in the cardiac rehabilitation group had not previously been aware of a risk for a heart attack or the potential need for major heart surgery. All of them were shocked and surprised that they had developed a problem with their heart that required them to undergo surgery. Participant 5CR had angina before his surgery and although he was aware of the risks associated with his angina, raised blood pressure and cholesterol, he felt that he managed his health well so risks were not applicable to him. Participant 1CR had mild angina before her surgery and had never thought of her risk for a heart attack. Because her condition was mild, she felt that she had never been informed of her risk by a health professional and had not come into contact with any information about angina other than what she had been told by a health professional.

My blood pressure was slightly high and I knew I was on medication. I mean I've been on medication for that for four years now so it was three years before I found out I had angina um so yeah I was aware of the risks um but I didn't think they would particularly apply to me because I thought everything was under control you know and my diet was reasonably..... I suppose I've changed my diet slightly, um I tried to make sure I don't eat too many biscuits. But I wasn't particularly overweight or anything.  
(Participant 5CR)

It never crossed my mind because the angina was very as I said very mild. Well to give you an example um the spray that I had I'd had it twelve months...just under twelve months because it only lasts for.... and I'd only used a small drop had gone. So I wasn't aware of it and I'd never even thought of a heart attack. (Participant 1CR)

### *Inherited risk*

Some participants reflected on their inherited risks and had ideas about possible implications. Others were aware of family members with the same condition but had not thought of their own risk. Participant (1CR) remembered that a number of men in her family (including her father) had died of heart disease but was not aware that she may have been at risk too. It appears that she felt she may have not been informed of her overall risk and therefore had no perception of it at all. However, she did reflect that maybe she had 'blanked it out'; this suggests that she may have been informed and aware of her risk at some point but had chosen not to think about it anymore.

I've never been very conscious about it although my father had a....and he was only 49 when he died of a heart attack um I've never really been very conscious of it. I don't know whether I've purposely blanked it out or not..... (Participant 1CR)

Participant 4C was aware that she may have inherited her condition (asthma) but was also aware that there have been environmental causes.

My dad's side of the family got bad chests and all sorts of things we don't know, but he still smokes today. So some of that was inherited, because I was thinking why have I got asthma you know why has it become that now sort of in my late teens at whatever and I was fine, I had been brought up in a household of smokers and think why now when they had all sort of stopped. You know it's a strong hereditary thing from what I have read, from my dad's side really and I don't know whether it's environmental, you know, as well. (Participant 4C)

Both participants with bipolar disorder displayed some understanding of the inherited or genetic risks that may have contributed to them developing a mental illness.

Participant 1EP had more of an assumed perception of his risk because so many people in his family had a mental illness, and participant 4EP had more of an informed perception of her genetic risk after reading about her condition and taking part in a research programme on genetic risk for bipolar disorder at a local university.

I've got plenty of ideas (laughs). Well my mother suffers with depression and I was talking about the problems with my brother... my brother's a paranoid schizophrenic, my other brother suffers with depression and my sister has suffered with depression. (Participant 1EP)

I agreed to take part in the bipolar research project and had the information about the study you know the background information for the study that I had was talking about some aspects of bipolar disorder and what they were interested in, and it made me think about my condition and to think that probably I have inherited part of the problem from my father and also reading about bipolar disorder in a book that the bipolar research project recommended also talks about genetic links. (Participant 4EP)

### *Environmental risk*

Participant 5EP talked about the risks in her work environment that may have contributed to her developing her condition (ADEM). Her ideas seem to be based on what she knew about her condition being caused by a micro-organism and her reflection on her previous working environment. For example, she had often visited people living in poor housing conditions. See the excerpt below where she talked about her thoughts:

Because it's so rare they did test on bacterium and viral and I know that they sent stuff to a lab in London but nothing conclusive came from it. I kind of thought that it could have been in my job. I go into houses that are not always well kept and I'm also around a lot of people that have got illnesses. So I thought perhaps I could have picked it up from someone or from any environment that I had been in. (Participant 5EP)

Participant 1C talked about the potential long-term risks to his health presented in his previous employment. However, his perceived risk was not enough to influence him to speak with a health professional.

One of the things that does concern me is in the 60s I spent not a lot of time but a number of (probably about 20 or 30) occasions and working in Aberthaw power station which was being built at the time ..of course there was this huge amount of asbestos dust floating that famous company Newells which is probably responsible for about 90% of all the people suffering from asbestos related lung diseases. We were there in force insulating every pipe and the atmosphere was just full of the stuff. So if anything I would be worried about or perhaps I'd consider I'd need to be checked for would be is it mesothelioma ...asbestosis something like that ...that is something I'd want to get directly checked for that but I haven't actually spoken to my GP about it. (Participant 1C)

### *Evaluating and making decisions about risks*

Some participants had to manage risks associated with their prescribed medication and consider those risks when making decisions about their life plans. For example, Participant 4CR was on immune suppressants and warfarin; she understood the risks associated with the effects of her prescribed medications and the implications for her future life plans (having babies) and her leisure activities. Her knowledge about these risks and ability to evaluate them within the context of her own life helps her to make decisions about her lifestyle and life plans.

So everything takes a little more planning but you can get around and looking to the future. Things like having kids will be a real ...it's possible but it will be a real issue so I have to go...I have to stop and I have to go on different drugs and I have to plan it. I can't just fall pregnant at the moment I'm on two different drugs that will both mash babies. You know Warfarin and Methotrexate are both horrible drugs for foetuses and there's no chance of getting pregnant at the moment, not that I want to now but in the future and things like just going off mountain biking there are big risks involved now if I fall over I fall off down a hill I could really severely bleed because I'm on the Warfarin and internal bleeding and things like that. So everything I do there is more of an element of risk and I have to think about my life a little bit more carefully than I used to.

Day to day I've got used to it, it's just a slightly different life. I mean I'm still eating my salads I'm still going to the gym and just more often um but I'm not going skiing with my parents anymore because skiing is too much of a risk. I can sit on the mountain but I'm not good enough not to wipe out an uh kill myself. But yes everything has a little bit more consideration in it now. (Participant 4CR)

Participant 4CR (a junior physiotherapist) also understands the implications of the risks presented by immune suppressants within the context of the risks in her work environment from exposure to patients. She had also thought about how this may affect her future career progression.

So I'm on Methotrexate which is an immune suppressor it reduces my immune system so I can't cope with colds, coughs, flu and things. I work in the health system I'm going to get ill all the time.

I'm beginning to get my life back and it's kind of how I planned it when I left uni so I'm working as a junior I'm doing everything I want to but it's slightly different so I'm going back into out patients I can't work in certain fields where I'm more exposed to risks so um your normal rotations as a junior. I'd have to do respiratory and I um intensive care but because of the risks that you have to take sputum samples from people. I can't have somebody coughing up into a pot near me because I have no... a reduced immune system so I would just constantly get ill I'd get all their pneumonia so I'm not going to be on call so I'm not going to ....so my career progression could be quite hindered by this so I won't have the experience for the necessary areas to move on. But I'll find a way. (Participant 4CR)

Participant 5EP was also on immune suppressants and she had an understanding of the associated risks and benefits, but she also understood the potential risks of withdrawing from them.

They dampen down your immune system so I'm more susceptible now to getting colds and things like that. I've got to be very careful, um if anyone is ill I've got to be very careful around them and I was given the flu vaccine last year because my immune system is so low. It has been lowered to help and as a precaution as well so yeah the main purpose is to dampen the immune system down and to try and... I think to stop my body fighting so much and to try and see if they can stop me relapsing that way um it is quite interesting to come off them. I come off them in a couple of month's time but there is another risk then I could have a relapse. (Participant 5EP)

### *Processing risk information*

Participants who had undergone bypass surgery and had procedures such as an angiogram reflected on the serious risks associated with them. These risks were presented to them by a health professional before to their consent. There was a risk of death with both procedures and there was an element of emotional reaction to the information. Here participant 4CR talks about risks that were communicated to her and her family. Although she may have been afraid of those risks and reluctant to think about them, nevertheless she had to gain an understanding of them and evaluate them in order to consent to the procedures:

"I think that the one that stood out is when I had my angiogram. Because Mr X he really went through everything and you kind of when you sign the consent you know you've got to have something done you've talked about it for ages um you've got to have this procedure done and you just want to sign it and say yeah... yeah sure go ahead do it but he really went so the risks are 1 in 20 of you know and there is a risk of death its very low um and this is what would happen and blah blah blah and I just wanted him to skip through everything and not think about what could happen um he really did explain everything and then said look I haven't lost anyone yet and you know all this stuff but um with the surgery it was .... Because you are on bypass you are a zombie for 4 hours and you know the risk of clotting and the risk of brain death and all that kind of stuff um and infection afterwards but they went through. (Participant 4CR)



Participant 4CR had good medical knowledge and understood medical language, biological processes and potential outcomes. However, the way she processed the risk information and evaluated it was affected by her emotional reaction to it. Participant 1CR also talked about her understanding of the risk of death associated with the angiogram procedure and her emotional reaction to the information:

“Um they were what they told me at the hospital at the time because it was a big surprise, a shock actually that I had to have a triple by-pass um.... Because I was told initially I was just going to have a stent but they couldn't do the stent when they gave me the angiogram they couldn't do the stent (laughs) the heart is a bit uh is not um.....would not be able to take it. There was a chance that if it.....when they did insert it...it could have.... If it had exploded, it explodes apparently. If it had in the wrong place even to a fraction it would have been.....that's it. So it was a bit of a shock. (Participant 1CR)

Both participants reflected on their knowledge and understanding of the associated risks of their procedures based on information that was verbally communicated to them in an 'informed consent' scenario.

### **5.5 Food literacy**

This dimension of health literacy represents the understanding of the relationship between food and health, the ability to read and interpret nutritional information provided on food labelling and the ability to evaluate and apply that information in order to benefit one's health. Healthy eating was a topic that was talked about in one lecture in the cardiac rehabilitation programme. Participants were given advice on choosing healthy foods and also managing portion sizes. However, all the participants in this group felt that they had eaten a healthy diet before developing a heart condition. None of them appeared to be overweight and they had no plans to make any significant changes to the way they usually ate. Dietary and nutritional advice is essential to diabetes education and the X-PERT programme was more centred on eating healthily to manage diabetes. The participants in this group had more concerns over their previous and current eating habits; they also had more concerns about their weight. Some of them were trying to eat healthily to lose weight and manage their diabetes. Some of them had already developed strategies for managing their diet for a while and others were learning how to do so in their X-PERT programme.

Some of the food literacy tasks involved understanding nutrition labels on food. The participants in the diabetes group were taught how to do this in their education classes; the nurse tutors taught them about different types of fats and also how to interpret information about fat and carbohydrate content. Most had not taken much notice of food labels prior to the X-PERT programme and had a basic understanding of food labels.

#### *Nutritional information*

Some participants were not aware of nutritional information that was important for patients with diabetes. Some had not previously followed a low fat or low carbohydrate diet and were unaware of the types of fats to avoid and the amount of fat and carbohydrate that was recommended for people with diabetes.

The X-PERT programme taught participants which carbohydrates to limit and how many grams of carbohydrates they were recommended to stick to per day in order to manage their blood sugar. This was first-time advice for most of them and they took it on board and began to read food labels and count carbohydrates.

Participant 2XP was on insulin and was desperately trying to bring her blood glucose to a lower level. She was concerned about her diet and was interested in making changes to her diet and limiting her carbohydrate intake. Participant 4XP was interested in keeping to a lower fat diet and was interested in looking for foods with lower saturated fat content. Below are some excerpts where they talked about this:

I'm more aware of the things to look at when I go shopping then you know. Saturated fats and all the different fats then you know and what is bad for me then you know and I try to avoid them. You know I mean no, I can't avoid them altogether but I look for the lower saturated fats than before. Before I didn't know anything about them. (Participant 4XP)

I've been counting carbohydrates and monitoring my food a lot more, trying desperately to improve my glucose readings. They are better, um I'm still not happy that they are right as yet but I don't think I can do anymore now until I see the diabetes nurse or one of the doctors which I'm due to in June. (Participant 2XP)

### *Managing food choices*

Having learned and understood information about the effects that food choices had on their condition, some people made changes in food choices and methods of cooking in order to manage their condition and cut down health risks, sometimes as a way of treating symptoms. Participants in the diabetes group made the most changes to their diet, especially after attending the education programme. They read labels more and eliminated foods that were high in fat and thought about the carbohydrate content in foods. They also used different cooking methods such as grilling or oven cooking instead of cooking in oil.

It's down to your diet and as I say prior to having diabetes it never used to bother me. Whatever went on the plate we ate you know but now sensibly because we still have our Sunday roast but our meat is cooked on a trivet. It's cooked out of the fat and its lean beef or its lean pork or its lean lamb the best you can get. Any fat on it we trim off and I don't have gravy and I use Vitalite (low fat margarine) and just put a bit of that on my potato and my carrots or cabbage or whatever we are having. (Participant 1XP)

We changed from... we got rid of butter. We changed to olive oil because it was healthy but we have since found out on the course that the vegetable oil that contains the rapeseed is even higher than the olive oil but olive oil is still a good choice. So we've made changes like that you know quite some time ago and I did try you know my husband likes having butter and I thought he shouldn't go without because I can't eat it but I found as long as it was in the house and I was putting it on his I was putting it on mine so the only thing to do was not have it here in the first place. (Participant 2XP)

In the cardiac rehabilitation group most participants had only made small changes to their food choices. Participant 4CR was the most careful about what she ate and chose to eat healthily in order to reduce health risk and to counteract against medication effects. Below is an extract where she talks about this:

Well you can see all the plants around me. I've got another whole room full of them um I'm very conscious of what I put into myself now um because I've got a lot of drugs in there that I've got to take so making sure that my nutrition is absolutely perfect that I'm eating nuts I'm eating healthily. Yes absolutely. I don't cook with salt um you know everything is monitored including my blood pressure so I'm making sure I maintain a good blood pressure and I eat healthily too so I make sure I cut down the risks. (Participant 4CR)

Participants in the expert patient group did not talk about food choices in relation to their condition and there was just one participant in the comparison group who talked about food choices in relation to managing her condition. Participant 4C had purchased a book about treating symptoms with food and sometimes chose particular foods that she thought would help her manage her asthma symptoms.

It's all about using food to treat symptoms and things like that and the main thing is for asthma that I was reading was you know chillies, coffee, all the things that act as a natural decongestion are really good. So if I am feeling particularly muck or have a bad cold or whatever I will make sure I have chillies in virtually everything. The way everything runs when you have had a hot curry, you know it really did seem to help so I was using that as a bit of a bible at one point, this is quite a few years ago now. (Participant 4C)

### *Portions*

Participants with diabetes were concerned about the portion sizes that they had previously been eating. Both participant 1XP and 4XP had been eating more porridge than was advised at the X-PERT programme. Participant 4XP had known that porridge was associated with lower cholesterol levels and had assumed that the more she ate the lower her cholesterol would be. Participant 2XP also became more aware of portion sizes in foods that were high in carbohydrates.

I think by going to these meetings it has helped me because I now know what could happen to me then you know um and when like they were saying the little portions because in my mind when they said to me porridge is good for you it will lower your cholesterol I was having a basin full of porridge in the morning and I'm saying to (husband) and he's said "that's an awful lot", "I know it is" I said "but it lowers my cholesterol so I will make myself eat it" and by the end of breakfast I was thinking oh God I'm full you know it is too much but never mind it'll lower the cholesterol, because in my mind that was helping me but then when I went down there and they showed me how much I should be having then you know I thought 'my giddy aunt', then you know I was really going over the top and it was ignorance more than anything because I didn't know. So it has helped and I would recommend it to everybody then you know. (Participant 4XP)

Since I've been going over there I've got to be honest the information is for me and when I was talking the first week we was there about porridge oats for breakfast and (another participant) sat opposite me well of course he was brought up next door to me and I said "about a cup full (laughs), a cup full per person, two cold cups of cold water he said "no a cup full for two" I said "don't be so daft". So the following morning I measured a cup full and then bloody ate it. So I thought well he's right well since

then I've reduced it by half to see the difference..... I mean If I hadn't been over there I'd be I'd be still chucking in a bloody cupful now. (Participant 1XP)

I didn't see that I had to count milk because milk is carbohydrate I thought semi-skimmed milk was ok I don't like skimmed but generally acceptable with dieticians and everybody. ....but I didn't see anything wrong with all the milk you know and it isn't really because you've got to have it, it's good for you but I think you know if you are an overweight diabetic like me you have to really balance it out, even if it's good for you. (Participant 2XP)

### *Timing*

Eating regularly is important in managing diabetes and most participants in the diabetes group talked about managing their food intake throughout the day in order to maintain their blood glucose levels throughout the day. Participant 1XP and 2XP had adjusted to eating regular meals for some time but participants 3XP and 4XP were more recently diagnosed and sometimes forgot to eat at regular intervals. Whilst participant 3XP felt the effects of skipping a meal, participant 4XP was asymptomatic and felt no effects of diabetes at all. Below is an extract where participant 3XP talks about the effects of skipping meals:

Yes, I try to eat regularly rather than you know.... I might be at work and it's fast and furious and you've got to get on to the next thing so might skip lunch and move on to the next thing and so you might skip lunch and not eat lunch until 3 o'clock and I scraped the car coming into the driveway the other day and I realised.... It was 3 o'clock and I realised it was probably because I hadn't eaten. (Participant 3XP)

### *Managing food with medication*

Some participants in the diabetes group needed to take medication around meal times. Participant 1XP took Metformin tablets and participant 2XP injected Insulin. They both monitored their blood sugar a few times throughout the day. Both knew how to manage the timing of their meals and medication regime and the impacts that both the food and medication had on their blood sugar levels throughout the day. Below participant 2XP talks about how she manages her medication alongside her diet throughout a day.

You have an injection in the morning and it contains fast acting for your breakfast and then the slow acting will work on your lunch and then fast acting in the evening meal and then the slow acting for the rest. Then through the night again and I felt sometimes my biggest meal was lunchtime rather than dinner time. The time when I didn't have the injection and the slow was working. The slow was working lunchtime and I wanted the fast working so I felt that would bring my blood sugars down much lower and the only way you can do that is have an injection with every meal that way I thought right I control what I'm eating, what I'm injecting and my activity what I'm doing and work it all out accordingly and that's basically what I'm doing. (Participant 2XP)

### **5.6 Interactive health literacy**

Nutbeam (2000) describes interactive or communicative health literacy as *"the social and personal skills and capacity that enable individuals to derive meaning from different forms of communication and to apply new information to changing circumstances"*. In this thesis a distinction has been made between interactive skills that involve interpersonal communication, (developing interpersonal relationships) and interaction with media resources.

#### **5.6.1 Interpersonal health literacy**

Interpersonal health literacy represents the abilities involved in the exchanges of information between people in health contexts (situations and activities relating to health). In this study these occurred inside (e.g. consultations, hospital settings or nurse visits) or outside healthcare settings (e.g. in the home or work place). These interactions were between participants and health professionals or lay health informants (e.g. friends, family or colleagues) or other professionals who they came into contact with and had discussions with about their health (e.g. social workers, care workers or community workers).

#### *Interpersonal communication skills*

Communications with healthcare professionals included requests for treatments and therapies, discussions about symptoms, treatment regimes and self-care strategies. Interactions with lay health informants (e.g. friends, colleagues, acquaintances and family members) involved discussions around treatments, symptom recognition, dietary advice and self-management techniques, working conditions and lifestyle. Interpersonal health literacy abilities that were important within interactions with healthcare professionals and lay health informants were: (1) the ability to listen to and

comprehend information that was communicated, (2) the ability to express one's own health concerns, (3) the ability to introduce and discuss one's own researched information, (4) the ability to reiterate information that was given from one person to another (e.g. between two different health professionals), (5) the ability to evaluate and assimilate information given from one or more persons (e.g. health professionals or lay informants) and (6) the ability to interpret information within the context of one's own circumstances.

Participant 4CR is an example of someone with good interpersonal health literacy abilities. She exercised all of the abilities described here; she had a good understanding of information that was communicated to her, she researched medication and treatment options and introduced information to discuss with a health professional, she had discussions with many different health professionals and checked out information given by one with another in order to get an alternative opinion. At times she was critical of some information that she was given and would sometimes check the accuracy of that information with a specialist.

Below are some examples of some interactions participants described in their interviews that displayed interpersonal health literacy skills:

**Some participants brought information to be discussed in a consultation:**

Um I actually got the information off the internet and took it into him that kind of thing. He then went onto the website and got more information for himself sort of thing. (Participant 5CR)

**Some participants expressed their concerns about medications:**

I approached the diabetes nurse and said I don't like the way things are going I feel like I'm injecting water because it doesn't seem to be doing anything. (Participant 2XP)

**Some were confident and competent in asking questions:**

I've chatted to my rheumatologist at the hospital and said oh have you seen patients with this? What do you see regularly? (Participant 4CR)

**Some were able to reiterate information to other health professionals:**

There is not always that communication straight away between my consultant and the GP they take a month for the letter to get to the GP and to say what needs to be done whereas if I see him and I tell him what's coming he kind of knows and if he's disagreeing then he's got a chance in the meantime to actually post a phone call and say..... which has happened in the past when there's been a disagreement over monitoring my certain drugs um and I've gone back and told him and straight away he's been....He's dealt with it where if he had waited for a letter it would have delayed things even more so there has been a lot of bouncing of information. (Participant 5EP)

**Some critically evaluated information given by health professionals:**

I don't rely on the GP because I have had negative experiences with them. They haven't come through for me and they left me at very dangerous levels where I was basically at potential stroke risk for 8 weeks and I had blindly trusted them but my INR was very low and after that I kind of lost trust in them and also because I'm shuffling, I'm managing 5 different consultants between Cardiff and London. I'm the only one that gets information from all of them I mean they all talk to each other but they don't retain the information because they have got so many patients so I find it easy to manage myself and just ask a GP when I need something but my rheumatology team are really good and they are the ones I go to for advice. (Participant 4CR)

Interpersonal communication was facilitated by abilities in other health literacy categories. For example, scientific literacy helped improve interpersonal health literacy. Participant 4CR is one example of this; she had good interpersonal health literacy skills and was active in healthcare consultations and often asked lots of questions. Her scientific literacy helped her communicate with health professionals at a particular level.

I have got a really good relationship with my rheumatology team who seem to be the most on top of everything and the most able to communicate with me knowing that I have got a good understanding. (Participant 4CR)

Her understanding of medical terminology and knowledge about her condition contributed to her interpersonal health literacy. She was able to interpret results of some of the tests she had and make sense of what they meant within the context of her condition. Her level of understanding seemed to give her confidence and helped her feel more able to be direct with health professionals in consultations. She seemed to give precedence to the ways in which she preferred them to communicate with her.



I'm now a lot more direct and because I have some knowledge and I have some medical understanding I don't like to be patronised by doctors when they say "oh you have got a bit of an inflamed aorta" I go "no actually I've got this I know my CRP level is rising and my ESR is ok" and they go "ok" and if I want something I ask for it. (Participant 4CR)

Sometimes participants preferred to make use of their functional health literacy skills to compensate for difficulties with interpersonal health literacy skills or at times when information that was being communicated to them was more lengthy and complex. Thus, some expressed a preference for written information to support information that was verbally communicated in a consultation. One participant wanted additional written information from a health professional because she felt that sometimes they rushed through information in a consultation and she wanted time to go away and process the information.

I think I sometimes ask for information, I sometimes ask for a print out um you know from my case notes of issues I need to read up further or if they talk very quickly, because the consultation times are very short aren't they? They talk quickly and I haven't necessarily grasped it all. I ask for a print out of that, I get it if there are any problems. (Participant 4EP)

Participant 3EP spoke English as a second language and expressed a desire for additional written information to help her understand her daughter's results given by a doctor; she sometimes asked for a written report and could understand the words better when she could see them written down.

Sometimes, sometimes our doctor they try to explain what you say. They try to explain to me but some of them I ask them to send me like a report to show this report to the next doctor to draft a letter to me. Other times I ask them about that because it makes me understand the words exactly. (Participant 3EP)

### *Developing interpersonal relationships with a health professional*

Interpersonal health literacy can also represent the ability to develop interpersonal relationships within various health contexts (e.g. primary care consultations, appointments with a nurse and visits to a regular pharmacist). In this thesis most of these relationships were continuous and likely to last over an extended period of time. Some participants had one or two main health professionals that they saw regularly

and others had several different health professionals. The most positive relationships appeared to be based on good communication skills (e.g. sharing information) and a mutual level of trust. Relationships that were not so positive tended to involve elements of insufficient or inaccurate information being given by a health professional and a loss trust or poor interpersonal skills on either part.

Participant 1XP appeared to get on well with all the health professionals he came into contact with, and his ability to form positive interpersonal relationships with them was related to his understanding of the information that they communicated to him and his adherence to their advice. He talked about how he got on well with his practice nurse in particular. He seemed to think he got on well with her because he kept a good written record of his blood sugar counts and was truthful when he showed her his results. Thus there was an element of mutual trust between them that seemed to underpin their relationship.

As I say with the practice nurse she is good..Because she said to me when I started first keeping a diary, she said “you are the only diabetic coming here that puts the truth in that book” because she can see some of them and there’s 8, 10, 12 she said “now you won’t be putting that in there will you”? I said “well, if I don’t put that in there how are you going to treat me”? If I come up there every weekend and its all fours and fives, fours and fives. I said “well it’s great at the end of the day I’m going down hill fast because counts are over what they should be and I’m not telling you the truth. It’s cheating look isn’t it”? She said “you are the only man coming here with diabetes that puts the truth on there”.  
(Participant 1XP)

Participant 4EP had particularly developed a good relationship with her GP in the 12 months since developing her condition. She felt that he knew her well and was very supportive to her; they had built up a level of trust between each other. He showed an interest in her recovery and helped her plan her future. She was comfortable discussing her concerns with him and they had a very open communication channel. Below she talked about their relationship; there was an element of mutual trust and respect for each other.

You know he trusts very much what I say and I feel like if I have got an infection or I'm not well he takes that on board and he listens. Because I think he knows that I'm level headed I think he knows my background he knows I'm not such a risk in terms of I wouldn't abuse my medication or anything.

(Participant 4EP)

I know when I need it and I know when I need to see him. So that way it's quite a good relationship and I've never had that sort of relationship with a GP before.

Participant 4CR referred to her relationships with a number of health professionals and particularly valued her relationship with her rheumatology nurse. She had developed a relationship with her rheumatology team where she had telephone access to them for any questions she had; they also called her to check how she was getting on. She chose to communicate with them mostly because she trusted their advice, as opposed to her GP for whom she had less confidence in.

I have got a really good relationship with some of the nurses and I've got a really good cardiac nurse and a really good rheumatology nurse across the road and my rheumatology doctor and the one in London they are all really nice and I've got lots of contact numbers for them which makes it easy to call up and say like for the last couple of weeks about this reaction and I spoke to (rheumatology nurse) and she said "ok do this la la la... and come back and see us" and she made the effort to ring in and say " how is it going you know have you tried this and who have you spoken to and have you seen your doctor". (Participant 4CR)

Whether participants had the opportunity to make use of their interpersonal skills in a healthcare consultation depended on the context of the consultation and the interpersonal skills of the health professional. Some participants felt that some health professionals had poor interpersonal skills. For example, participants 1EP, 2XP and 3XP sometimes felt that their GP was poor at communicating with them, participant 4XP also mentioned one GP in her surgery was a 'man's doctor' and felt he was not as good at communicating with her as the female GP in her surgery. Thus, poor interpersonal skills on the health professional side can hinder the development of a positive interpersonal relationship. Similarly, poor interpersonal skills on the patient side may also hinder a positive relationship. Participant 1EP seemed to have lots of interpersonal conflict with health professionals, this seemed mostly because she felt she was not getting enough information or the services that she wanted. She was uncomfortable interacting with health professionals who were not familiar with her

concerns and seemed to have less positive interactions with them than her regular GP who she felt knew her well. The following interview extracts illustrate some of the conflict that she had experienced with a number of different health professionals.

I go and see my doctor and he's not there, I can see another doctor and he can just fling me anything, it happened the other day. So I go back over that and I wasn't very pleased about him and I told the doctor my GP that I don't want to see that doctor again because he doesn't know me and I've seen him 3 times in 15 years so he doesn't know my history.

Some doctors they just won't listen, I come out in the end of May and I went to see the doctor because I'd lost my aspirin that was prescribed in (local hospital), I'd lost it. I went over there "it's not an emergency"; I said "well it is to me". I said "have you got my file in front of you"? "What were you taking aspirin for?" in his lovely Welsh accent and I just looked at him and I said "have you got my file please"? Yes he said "but we haven't got anything on here", I said "but if you open it up you see that I might have had surgery a couple of weeks ago. "I've lost my aspirin" "well I'm not giving it to you I just banged the door (whispers) "f\*\*\* off, you ever, ever (I could be on my death bed) make me see that man again you are all out of a job, there will be no building left. I'm not that desperate to see that f\*\*\*ing plank Plaid Cymru-ite. All right, we understand". (Participant 1EP)

### 5.6.2 Interactive media health literacy

Interactive media health literacy represents the abilities involved with accessing and interacting with internet media information sources, and critically evaluating the quality, reliability and relevance of *media based information*. It also includes the ability to communicate with others in online discussions, on message boards and emails and using the information to make decisions about managing one's health and introducing it in consultations in order to discuss in further detail with a health professional. Some of the interactive media resources that participants accessed were health related websites, Google, You Tube (a video sharing website), health organisation websites (e.g. Diabetes UK and the MS Society).

#### *Accessing internet information*

Most participants used relatively simple methods of searching for information online; some used Google to search for general information about their condition.

However, participants who had more health-related educational qualifications (e.g. participants 4CR and 5EP) and experience of working in healthcare services had more

sophisticated methods and knew how to access medical research. Below are two extracts illustrating some general methods of accessing information:

.....Diabetes UK and some of the NHS health...you know just Google diabetes. Basically and read through whatever you get..... (Participant 3XP)

If I'm looking for information say on heart surgery I just type in heart surgery on Google and see what comes up. (Participant 5CR)

Participant 4CR had more advanced skills in interactive media health literacy than other participants. She was a physiotherapist and experienced in using the internet in her medical education. She had knowledge of where to look for relevant information. Before her surgery she researched the surgical procedures online and was able to find out that there were two types of valves that could be used to replace her damaged heart valve. By the time she had a consultation she already knew some of the information that would be introduced for discussion by the cardiologist.

She also had looked online for information about surgical procedures some months after her surgery, and watched videos of heart surgery on You Tube.

She already had some understanding of what had been done to her body during surgery but she used the videos to expand her understanding and reduce some of her anxieties. She also looked up information on her medications and the side effects that they produced. She used some websites to communicate with others who had a heart condition and ask them questions about some of the effects she was experiencing from her surgery and also ask questions about their experiences. At one time when she was concerned about her scar she even shared pictures of her surgery scar with another person she communicated with on the GUCH (Grown Up Congenital Heart Patients' Association) website. Below are some extracts where she talked about engaging with information through internet media sources:

I did a little bit of research before I went to see the surgeon and said so I know there is a pig valve and a mechanical valve.....

.....having the GUCH online and being able to say...honestly being able to just put a question out there and say "when I breathe in why does it sound like my chest is popping"? I watched a few surgeries on You Tube as well in kind of... not in a morbid sense but I needed to see what happened. (Participant 4CR)

### *Appraising information sources*

Participants critically appraised the quality and reliability of some health information that they had found on the internet. Some found it difficult to identify which information sources were most reliable and others were more critical and had ideas and strategies that they used to access and select information that they felt were more reliable and relevant to them. Below are some quotes that exemplify the experiences they had in evaluating the quality, accuracy, reliability and relevance of some of the health information they came across on the internet.

#### **Quality**

Some of it you've got to avoid. You've got to use your own savvy to distinguish between what's good and um what's bad. (Participant 1EP)

#### **Relevance**

I was looking things up on the internet and I was going on to Diabetes UK but everything was a bit patchy and I couldn't put it all together. (Participant 3XP)

#### **Reliability and relevance**

I find it confusing actually because if you read two or three different articles they tell you completely different things but I think you just try and put together things that you can actually identify with yourself and um that's it basically. (Participant 5CR)

### *Selecting relevant information*

Some participants talked about how they filtered out certain pieces of information that they did not need or that they were sceptical about and selected information that they thought was more reliable and relevant to them and their particular information needs. Information from pharmaceutical companies was sometimes overlooked and there was scepticism about some of the information that they provided. Below is an excerpt where participant 4XP talked about not needing the promotional information, but she was interested in personal stories of other people with diabetes that was provided on some websites.

What these people on the internet are saying buy this buy that to help you then, really speaking no I don't need to have all that but some of the interesting parts then you know.... different people that have had diabetes then you know.... I have read about them and how they cope with it and that then.

(Participant 4XP)

Participant 4EP found some information sites did not provide her with enough relevant information about her condition. She struggled to find enough information that was relevant to some of the symptoms that she was experiencing. For example, she looked at the website for the Encephalitis Society and did not find it as informative as the Multiple Sclerosis website. Some of her symptoms were similar to multiple sclerosis so she chose to use that website as her main source of information on how to cope with and manage her symptoms.

I got more from going on to the MS society website because they seem to have a lot of information and it's quite good information and even though I went onto the Encephalitis website there still wasn't very much because MDEM was more common in children after inoculations, for some reason it can be a bacterial or viral disease so I just found I actually got more information by going onto the internet and going on to the MS site than I did from the hospital and going from the consultant. (Participant 4EP)

### *Substantiating Information*

Whilst some participants were comfortable with engaging with online information and using it to make independent decisions about their health, others sought to substantiate some of their findings with a health professional. Participants did this for two main reasons; to ensure that the information online was correct or applicable to them and sometimes because they felt that it was something they 'should do'.

Participant 4CR checked information that she had looked up about some of her symptoms with one of the cardiac rehabilitation nurses.

I have checked a few things with the nurses I still get a lot of bugs in my vision I call them bugs or warfarin bugs and I was told that that would last 6 weeks and I'm now 12 weeks post and I still get these stars. So I just looked it up online you know all these ophthalmology websites and all this kind of stuff and it was oh tell your nurse if you are still getting occluded vision after six weeks and they said it was to do with the warfarin and it was bad and I was a bit worried, but I went to the cardiac nurse at the last session and said "is this right" and she went "oh its from the by-pass machine don't worry".

(Participant 4CR)

Participant 4XP used the internet to look for details about her medications. However, it seemed that she wouldn't always take the information on board without a discussion about it with her GP. She was ambivalent about whether she should be engaging with online information at all or make any decisions based on the information that she had found. She appeared to have a sense of obligation to discuss the information with her GP rather than to take any immediate actions herself.

...when I go on the internet like I have a lot of emails coming through like I have got a few there for diabetes that I haven't picked off yet, and Statin and when I started reading them God it really bothered me then and (husband) said "should you be reading them"? I said "well I don't know really, you know". Should I listen to them or should I go and take my problems to the doctor and speak to the doctor face to face about it then you know? I mean there are things that I have printed off I have taken with me to the doctor and I've said "I'm not happy about this". (Participant 4XP)

Some participants used their interactive media health literacy skills to advance their understanding of information that they had acquired through other health literacy skills such as functional and interpersonal skills. Some participants talked about looking for further information online to expand on the information that was given by a GP or to help them process the information in their own time.

Well normally he would explain to a point what the impact of the drug will be, but if you want to look it up in more detail you can always go on the internet or alternatively the little bit of paper work that comes with them will tell you in detail what you have to do. (Participant 1C)

Consultants tend to rush through everything with you but on the internet you can take your time to digest it in and then you can take that information with you and you can go into your doctor next and ask him. (Participant 5EP)



### *Informing health professionals*

Participant 5CR searched for information to help his GP diagnose a rash that he had. He was able to find relevant information and take it in to his GP, who then searched for further information.

I actually had a rash....actually on my penis which um was thought to be called a thing called balanitis um which the doctor had never heard of um so I went back to him the following couple of weeks after, in fact I had to have a biopsy for it. Um I actually got the information off the internet and took it into him that kind of thing. He then went onto the website and got more information for himself sort of thing. (Participant 5CR)

### *5.7 Distributed health literacy*

Accessing, understanding, evaluating and using health information was not always an individual task. The term “distributed health literacy” is used in this thesis to describe the ways in which participants often drew on the health literacy abilities, skills and practices of others as a resource. Health literacy was dispersed through social networks and there were some health literacy practices that participants sometimes devolved to others and at other times collaborated with others to manage their health and make health-related decisions. In this chapter distributed health literacy is described in terms of what it is and in the next chapter distributed health literacy will be further discussed in terms of what participants achieved from it.

Distributed health literacy was important in three stages of knowledge acquisition and use; developing a shared knowledge, support with accessing and evaluating information, and supporting communication.

#### *Shared knowledge and understanding*

Participants often sought advice from personal contacts who had lay or expert knowledge of their condition. For example, participant 2XP was a member of Diabetes UK and attended regular meetings and fundraising events in her community. She had access to information and advice from other people with diabetes in addition to expert advice from guest speakers at these meetings who helped her make decisions about how to manage her diabetes. Below are some extracts from interviews where she and others talked about knowledge that was passed on to them:

We have invited all specialist people to do with diabetes to come and talk to the group, give me and others the opportunity to ask the experts questions, and they know the answers to questions that my GP couldn't really give me an answer on. (Participant 2XP)

It's good to talk to other people and you know see how they treat their diabetes and if they have a problem that you are having maybe they are handling it better and you could learn something from just talking to somebody. (Participant 2XP)

I took inhalers for years before I realised you are supposed to rinse your mouth out, because you can get oral thrush and whatever from it. I've never had oral thrush but I didn't know you were supposed to do that. It was the psychiatrist in work who was asthmatic and she just mentioned it to me you know it's important to rinse your mouth after you've..... I didn't know that. (Participant 4C)

### *Accessing and evaluating information*

Friends and family members often accessed online information for those who did not have computer literacy skills. The information was then usually passed on to the participant or discussed between them. Below are some examples from interviews:

I don't use the computer personally but I get my husband to do it. So if I want to know anything I got him to have a look on the internet and print something out that I'm particularly interested in. (Participant 2XP)

If I want to know something I will ask him to look it up on the internet for me simply to get him to be aware you know and it's not that I'm not capable of finding things for myself but if I ask him to do it he will look into it and he's very analytical. (Participant 3XP)

### *Support using information in hospital and in consultations*

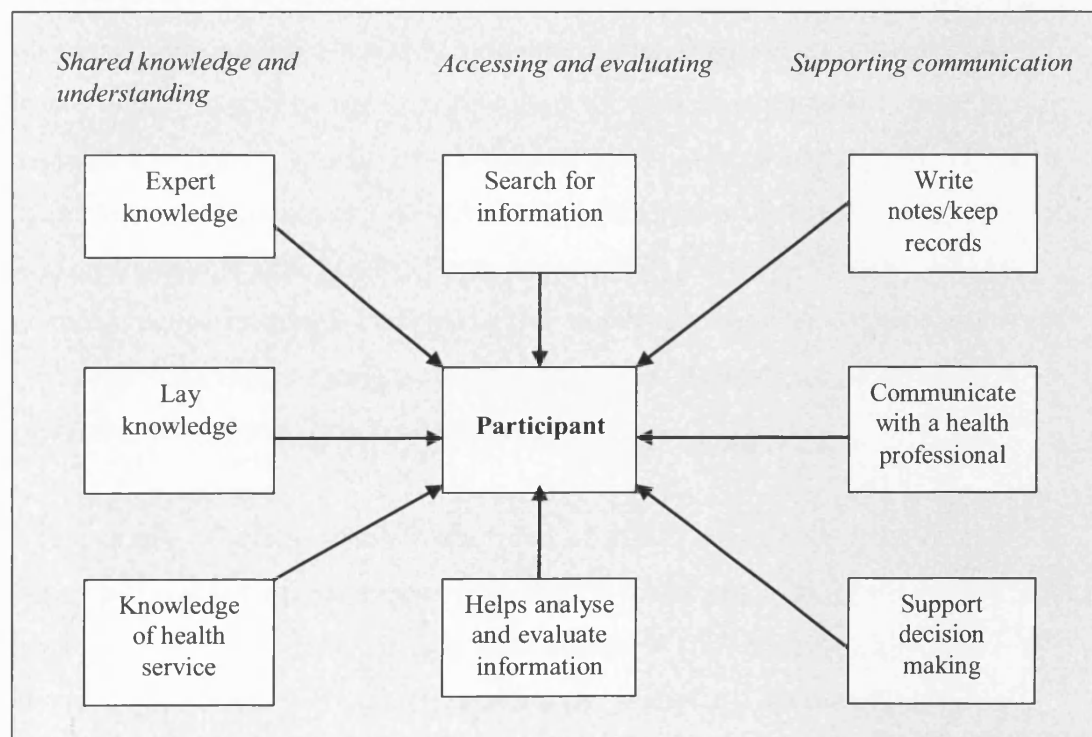
On some occasions family members or friends listened and acted as note-takers and at times had some input into the consultation. In some instances with the cardiac patients family members communicated with health professionals on behalf of a participant at a time when they were in hospital and too ill to communicate or in an emotional state that made it difficult for them to take in or process information. Two participants talked about having another person present at the consultation to help them process the information being communicated to them. It is noteworthy that these two participants had both worked in the health profession, were relatively young females (23 and 32) and both had serious conditions that at times had impaired their short-term memory. Both were also quite highly skilled in terms of health literacy practices

themselves but still sought and needed the support of friends and family in processing and understanding health information provided in healthcare consultations.

I always have someone with me, even from working in the health profession I was always taught if you are going to see a doctor have someone with you because you don't always process what's been said um so it's good to have that person with you (Participant 5EP)

Below is a representation of how health literacy practices were distributed across three stages of information acquisition and use.

**Figure 5.1 Distributed health literacy practices**



### 5.8 Critical health literacy

Nutbeam (2000) describes critical health literacy as *“the cognitive and social skills that enable individuals to critically analyse information and also use it to support effective social and political action, in addition to individual action”*.

Part of this description covers the critical analyses of health information, which includes the ability to appraise the quality, reliability and relevance of health information that is communicated person to person, in writing and through media sources. However, in this thesis critical analysis is also described in terms of interactive dimensions of health literacy (for example, the ability to critically analyse verbally communicated or internet-based information).

There was little evidence of social action; most participants were concerned with their own long term condition and although some attended support groups (e.g. MIND) or joined online support groups (e.g. Asthma UK) most people’s motivation and goals associated with joining these groups seemed to be on an individual level. The one example of more community level action was in terms of diabetes health promotion. Some participants were involved with a community branch of Diabetes UK and attended regular meetings. Participant 2XP and her husband were actively involved with organising expert speakers, raising awareness of diabetes, fundraising and recruiting members in their local community.

One example of critical health literacy and its impact on individual action might be the critical analysis of information provided by health professionals or critique of health services that inspire a person to be critical of and take action against health services. Participant 5EP had doubts about the quality and amount of some of the information she had been given by health professionals at the hospital; she also had researched information that was not entirely consistent with the information that she had been given. She had knowledge about what her rights were as a patient and had acted on them by asking for copies of her medical notes.

I know that because of the Freedom of Information Act you are entitled to see your notes and they charge you quite a lot of money if you want photocopies of them £50 um I know you are entitled to that and you are entitled to change your... and you are entitled to have a second opinion and without having prejudice about making that decision um and you are entitled to see your... well you should be entitled to see your patient care plan as well which is very important I think so you know what's happening um and that I kind of know from working in the hospital really. (Participant 5EP)

She also had strong ideas about patients' rights for information and was concerned that some patients were not always empowered.

I think it's so important that patients know that they can ask questions and they should have this empowerment. So I don't think it's always been clear to them.

I think also on (hospital) wards you're not really made to feel on wards that you have these rights you have a patient care charter you are entitled to certain things.... (Participant 5EP)

When asked about similar issues most other participants were not particularly aware or concerned about their rights or the rights of others.

### 5.9 Civic literacy

Civic literacy is described in a model of health literacy by Zarcadoolas et al., (2003) as an "*understanding of what it means to be a citizen and how this relates to health*". Making individual decisions for the benefit of the health of the public would be an example of this. In this study there was no evidence of this. However, some participants had knowledge about their rights and responsibilities in their role as a patient in the UK National Health Service. Civic literacy according to Zarcadoolas et al. (2003) also encompasses the distribution of health-related social capital. Social capital is defined as "resources embedded in social relations among persons and organisations that facilitate cooperation and collaboration in communities" (Gittel & Vidal, 1997, p.16). There was little evidence of social capital talked about on a community level apart from that experienced by some of the diabetes patients who attended their local branch of Diabetes UK meetings. Social capital was best exemplified in smaller social networks that were evident in some of the cases of distributed health literacy.

Zarcadoolas et al. (2003) also describe civic literacy in terms of a critical understanding of the media and how health information is put together and disseminated in TV, radio, print and the internet. Some skills associated with this dimension of civic literacy have already been incorporated into interactive media health literacy. Other skills overlap into the definition of “public health literacy” as described in the next category.

### **5.10 Public health literacy**

Public health literacy is defined by Freedman et al. (2009, p 446) as “ *the degree to which individuals and groups can obtain, process, understand, evaluate, and act on information needed to make public health decisions that benefit the community*”.

There has been some discussion in the literature about whether public health literacy should be interpreted in terms of health literacy for the public (mass distribution of health literacy within the population group) or literacy about public health. Evidence of public health literacy in this study was related to the latter description and was an understanding, appraisal and actions taken based on health information aimed at the general public. There was evidence of engagement with public health information, particularly about swine flu. The research took place over a time that swine flu was a public health concern talked about on TV news programmes, and reported in the press on a daily basis. Participants varied in their knowledge of what it was, what the symptoms were, what to do if they suspected they had it and their knowledge about how health services were dealing with it. Most information that people had was through the media. Some had read articles in newspapers and watched TV reports. Most participants thought that the threat was overestimated and “over-hyped” by the media. This led some of them to disengage with the public health information distributed through the media. Elements of risk literacy, public health literacy and civic literacy were combined to form a perception of one’s risk of contracting swine flu. Most participants perceived their risk of getting it as low.

Personally I just feel it's over rated, they are making a mountain out of a mole hill then you know. I mean I listen to it on the television and people phoning in sick saying they have got swine flu and they haven't then you know and I just feel. Here again in this country then you know and they just go over the top. Sorry that's my opinion and it's his opinion as well like you know. I just feel 'oh for God's sake' then you know. (Participant 4XP)

I think as with lots of things it's over-hyped, perhaps they are very frightened about a possible pandemic and they want to get the message across to people but I think they have gone over the top and the problem I think with that is if you do that you lose people they just switch off and don't take advice of basic messages that there is. (Participant 4EP)

Now personally I think this has gone absolutely ridiculous apart from yesterday that's not important but all this media coverage they seem to.... They are frightening people, I mean if people are that way inclined I think it can have a very bad effect because there's flu every winter and hundreds and hundreds and hundreds of people get it and unfortunately some people die but you don't hear about it. I do think that they have gone right over the top and everybody I have spoken to thinks the same. (Participant 1CR)

Some participants who were immune suppressed (4CR, 5EP) or had diabetes (2XP) demonstrated awareness of the risks that contracting swine flu would have on their condition. They were aware of how they could protect themselves from swine flu and considered having the new swine flu vaccination that was about to become available.

I don't think it is available yet it was supposed to be the end of August but I don't think it has come into effect yet. I think they are going to give it to children, nurses, think it is mainly frontline staff and I think those with underlying health conditions. I know because I have got an autoimmune disease I'd be able to have it. (Participant 5EP)

### 5.11 Cultural literacy

Cultural literacy is described by Zarcadoolas et al. (2003, p64) as "*an understanding of the power of cultural practices to influence the health status of individuals as well as how they define a healthy lifestyle.*" Cultural literacy can incorporate the cultural practices of anyone who identifies themselves with others in terms of values, perceptions and actions. There were some examples of cultural differences across age groups, and religious and ethnic backgrounds. For example, some older (over 70 years of age) participants in this study were particularly compliant to medical advice and treated a health professional as the only source of information compared to some

younger participants who were more critical of advice and used other sources of information. These differences were mainly because of the different perceptions of the roles of health professionals and differences in the value of information and advice communicated by a health professional compared to other sources of health information.

Participant 3EP was from the Sudan and was Muslim; she had recently developed her own cultural literacy by learning about particular religious beliefs that related to health. For example, she had recently learned that there was advice given in the Koran about how one should eat healthily. This was not something that she knew about or had followed previously.

In the words of the Koran there are instructions about healthy foods and the time.

The Koran says you have to have 5 meals after every four hours you have to eat something, a little bit not a big meal and another thing I tried myself. (Participant 3EP)

She also had recently acquired knowledge of Muslim beliefs about a connection between pigs and swine flu.

Just yesterday, it is a very strange thing that happened honestly I heard that prophet Mohammed speaks about this illness after 400 years and he said that in his book that there is an illness come in the last... he says that about many years, after many years the illness the illness came from the ... you know the name of the animal.

Yes, the pig it comes from it this flu and he says that it will be going... this flu it will continue until the last animal was killed. You know we are not allowed to eat it because this animal eats everything you know. It eats rubbish... everything so there is something in his meat that is not good and I think that they discovered that there is like snails in his meat and most of people they eat it not very grilled.  
(Participant 3EP)

She had become more culturally literate since moving to the UK. She was aware of the differences in medical culture in Sudan and in the UK. She knew that medical care in the Sudan was poor and hospitals were ill-equipped to deal with the needs of her chronically ill daughter. She knew that moving to the UK would help her daughter. She was adapting to UK culture by attending college courses and using library



services to read health books in order to understand more about health and health services.

I try to do that I try to make like membership in the library to help me about health book. Most of the time I try to have information from listening or watching but I found that to read is a good thing. This is something that I take from the culture of this country. (Participant 3EP)

She had some awareness of the differences in healthcare services that may help her daughter in different parts of the UK and even the United States. She was using this cultural knowledge and understanding to make health decisions for her daughter and in deliberating whether she should move to London or to the United States to access better healthcare for her daughter.

You can't compare between because in Sudan it is not very easy to know about your condition. I think the doctors are very qualified but the machines. There's not technology machines about investigations and do many things like eh like um x-rays or ultrasound or something that even it is available it is very expensive.

I feel that because every day there is something new in treatment or medical things. I saw for example in the States there is like more technology than here in the UK and in England there is more technology than Wales. I have many relatives for example in London and I saw by myself. The doctors there and the hospitals there use more technology than here, so most of the time I feel that the doctors here have a red line to stop behind.

So sometimes I think about to go to America, I have a friend there and she can send me an invitation to go to the States. She told me there is a good medication there and if your child has a problem you can think about to go to everywhere, to open up all the doors. (Participant 3EP)

### **5.12 Chapter summary**

This chapter has explored how participants practised health literacy and has framed these practices within new and extant categories of health literacy. These categories were interconnected and participants drew on a range of health literacy skills in one or a number of categories depending on the health context. Functional health literacy was the most basic category and provided a base-level of skills that facilitated other skills in other categories. For example, skills in functional health literacy were necessary to gain knowledge and become more aware of risks (important in risk

literacy), to learn about biological processes and research (scientific literacy) and to gain access to and interpret internet-based information (interactive media literacy). Participants had the potential to develop their functional health literacy and other categories of health literacy through their engagement with a variety of health and medical based texts ranging from information leaflets picked up in GP surgeries to medical text books and dictionaries.

There was evidence that some participants who had a good level of scientific literacy (e.g. participants 4CR and 5EP) had a detailed understanding of their condition, made decisions on methods of treatments and were able to engage with research evidence to make further health decisions. Participants who demonstrated a degree of risk literacy were aware of inherited and environmental risk factors that contributed to the aetiology of their condition. Risk literacy also helped some participants make decisions about treatments, lifestyle and self-management.

Participants who had a good level of both scientific literacy and risk literacy combined (e.g. participants 4CR and 5EP) seemed to have a good understanding of risks associated with medications and environmental risks and were able to understand some of the risks involved with invasive surgical procedures. Those who did not demonstrate a good level of scientific literacy and risk literacy (e.g. participant 1CR) seemed to have less awareness of genetic or inherited risks associated with their condition.

Food literacy was important in the management of diabetes, some participants' skills in food literacy helped them make healthy food choices, manage their diet in terms of portion size and helped them plan a regular eating pattern that coincided with a regular medication regime and stabilised their blood sugar. Whilst functional health literacy was a basic ability grounded in the ability to read and write that led on to other categories, scientific literacy, risk literacy, and food literacy were more grounded in the ability to learn and use factual knowledge.

Interactive forms of health literacy were grounded in participants' abilities to interpret, appraise and communicate health information. However, interpersonal relationships were based on mutual trust and more equitable exchanges of information. A good level of interpersonal health literacy (i.e. the ability to

communicate with others) was facilitated by skills in scientific literacy; those who understood medical terms and biological processes had positive exchanges of information with some health professionals and seemed to be satisfied with the information they had received. Good functional health literacy skills and interactive media skills sometimes helped participants engage with information to expand on verbally communicated information or enabled them to process the information over a longer time period. Interactive media health literacy incorporated skills in seeking, appraising and selecting relevant information from online sources. Participants sometimes sought the support of health professionals to substantiate their findings and to make decisions.

Health literacy was distributed through social networks, and skills in all categories of health literacy were shared and supported with friends, family members, work colleagues, and support workers. The main tasks that distributed health literacy influenced were: the development of knowledge and understanding health information, accessing and evaluating it and supporting health communication. Critical health literacy was demonstrated in community action by participants who were organising members of a local Diabetes UK branch and in individual action by a participant who was concerned with her rights as a patient. There was some evidence of critical literacy in participants' critiques of the way public health information was covered in the media, and there was an overlap where the civic element of social capital was similar to distributed health literacy as a resource that people could draw on from their social networks. Public health literacy was practiced in participants' knowledge and perceptions of public health issues such as swine flu. There were connections between risk literacy, civic literacy and public health literacy in the way participants' evaluated public health information and applied that information to their own health concerns.

Cultural literacy was most evident where participant 3EP had cultural and religious beliefs that she incorporated into her beliefs about health and where she was integrating into UK society and gaining an understanding of the availability of different health services across the country and between other countries (including her country of origin). Her knowledge of these differences influenced her desire to move to gain better healthcare for her daughter.

This chapter has identified participants' health literacy practices (i.e. experiences with health information and services) across different health contexts and set out eleven health literacy categories. The overlaps and interconnections between them have also been identified. The categories identified here contribute to what is known about how health literacy is practised and introduce new ways of viewing health literacy in different health contexts. The next chapter will answer three research questions: *(3) How is health literacy developed over time? (4) What are the motivations, barriers and facilitators that influence its development, and (5) what is the relationship between health literacy and informed decision-making?* It will explore how participants developed health literacy abilities, skills and practices associated with these health literacy categories over time and what influenced or inhibited their development of health literacy. It will also use evidence of health literacy practices in different health contexts to illustrate how the development of health literacy activates some participants to become informed decision makers.

## **6.0 Health literacy pathway to decision making**

### **6.1 Introduction**

The aim of this chapter is to explain the relationship between health literacy and informed decision making. An analysis of themes that related to both health literacy categories and involvement in healthcare consultations helped identify a range of knowledge, attitudes, behaviours, skills and practices (abilities and tasks), and actions that facilitated or inhibited informed or shared decision-making. Participants who demonstrated greater health literacy skills in their interviews and during the observation period seemed to have the following qualities:

- knowledgeable about their condition
- skills in self-managing it
- active in information seeking and use
- communicate with health professionals in an assertive manner
- involvement in seeking or negotiation of treatment options

Participant 4CR is an example of an ‘ideal (health literate) patient’; she had more advanced health literacy skills than all other participants and had the above qualities. Participants who demonstrated lower health literacy skills seemed to be less active in managing their health and less active in consultations. Thus, they had limitations in some of the qualities mentioned above.

The framework approach to data analysis helped the student map out these qualities as a set of health literacy-related *stages* that lead to active involvement in healthcare consultations (including informed and shared decision making processes). This chapter will describe these stages and motivators and barriers that inhibit progression through the stages. A conceptual model will be presented and data extracts will be used to support the findings.

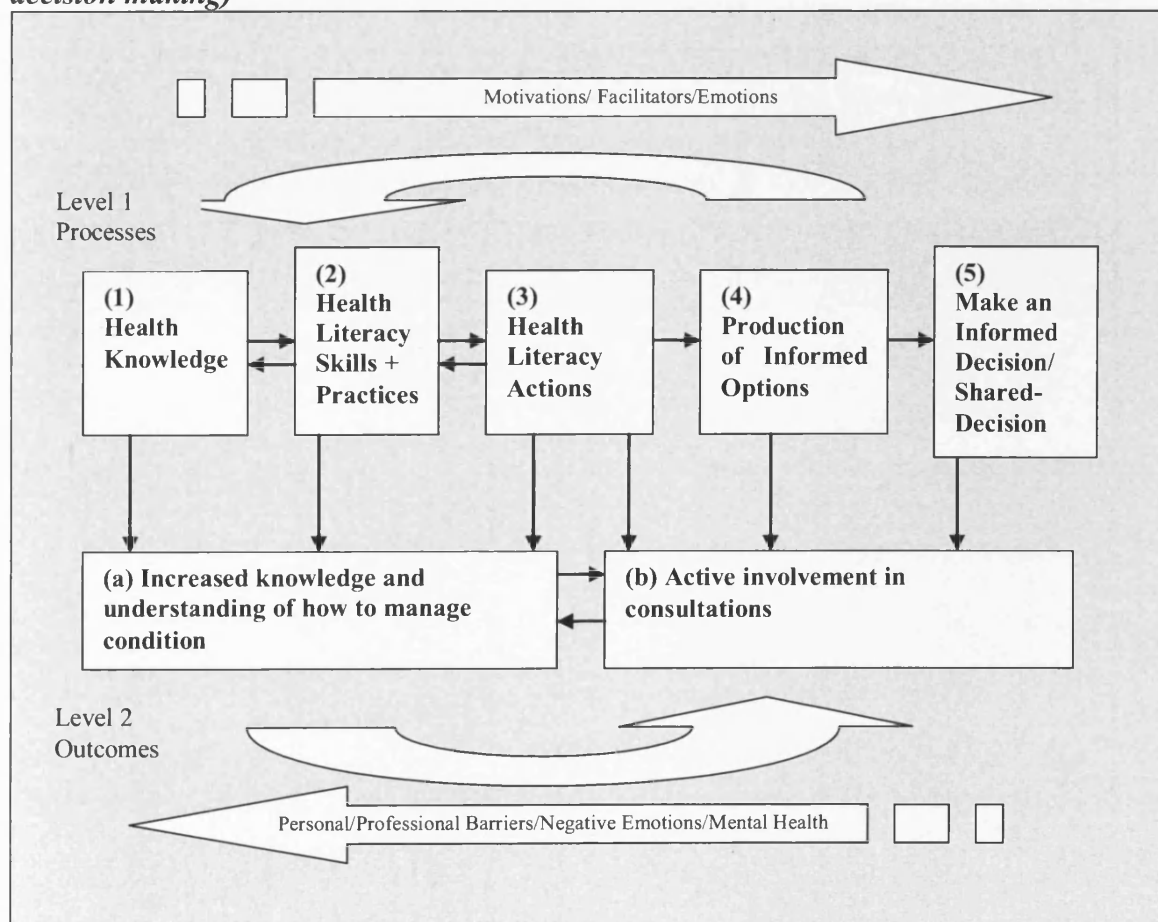
The chapter is separated into three sections: section (1) describes each stage in the pathway model; descriptions are provided of how people move from one stage to another (either on an individual basis or with the support from others).

Section (2) describes the personal motivations, emotions and facilitators that help people progress along this Pathway Model. Section (3) describes barriers raised by health professionals and personal barriers that delay or inhibit progression between stages of the pathway.

### 6.2 Section 1: Linking health knowledge and health literacy to informed decision making

Data analysis identified that there was a set of stages that participants progressed through as they increased their knowledge and understanding of their condition, learned how to manage it, actively participate in discussions with health professionals, and make informed self-management and treatment decisions. In some instances participants progressed through all stages, whilst at other times participants progressed through the first two or three stages. Progression through these stages is presented in a theoretical model mapping a *health literacy pathway* from health knowledge through to decision-making (see figure 6.1).

**Figure 6.1 Pathway Model (explaining a health literacy pathway to informed decision making)**



### **6.2.1 Stage 1: health knowledge**

The top level in the model includes five stages along the pathway; each stage requires a more complex set of level health literacy abilities. As participants progress through each stage they develop their health literacy further. The first stage is **health knowledge**: this represents a person's basic knowledge about health in general and knowledge in respect to their own health concerns. This knowledge has been formed through reading about health (functional health literacy), interactions with health professionals and/or health educators (interpersonal health literacy), discussions with friends and family (distributed health literacy) and interactions with media health information (interactive media health literacy). In the first interviews participants had varying degrees of health knowledge; some participants had a basic general knowledge of health but little knowledge of a newly diagnosed condition, others had been living with a condition for some time and had built up a substantial amount of knowledge. Below is an example of the knowledge that one participant demonstrated about her condition:

I fell ill in July 17<sup>th</sup> last year with flu like symptoms and it developed into what they call um part of the encephalitis group but it's called ADEM (Acute Disseminated Encephalomyelitis). Initially it was called IDEM it's called acute dissemination it's to do with acute deterioration of your myelin sheath basically and with all this being attached to your nervous system is all being attacked.

I've got nerve damage mainly to the right side, I've got a bit on the left but it's mainly the right side that I feel a lot of damage um I've got optical neuritis which is blurring of the eye. I've got damage along the optic nerve there and as a result I have a lot of nerve pain like in my head. (Participant 5EP)

### 6.2.2 Stage 2: health literacy skills and practices

The second stage of the model is **health literacy skills and practices**: health literacy skills represent competencies in listening, speaking, arithmetic, problem solving, and decision making that are used in 1) information seeking and use of information, (e.g. using computer, to seek information, skills in information seeking, critical analysis of information), and (2) self-management skills such as understanding medication dosages and understanding blood sugar or INR measurements.

Health literacy practices are the tasks that participants carried out that used these skills (e.g. searching for health information, balancing diet with medication, self-monitoring blood sugar/INR). Some of the health literacy skills at this stage can actually increase health knowledge, thus there is a feedback relationship between health literacy skills and health knowledge. One example of this feedback relationship is the ability to successfully access and use information in order to further one's knowledge of a condition. Below are some examples of health literacy practices and the categories of health literacy skills that they draw on:

Accessing online information Evaluating information sources Using social media (web chat)	}	<b>Interactive media health literacy skills (see section 5.6)</b>
Engaging with research	}	<b>A scientific health literacy skill (see section 5.3)</b>
Accessing written materials	}	<b>A functional health literacy skill (e.g. writing to organisations for information (see section 5.2)</b>
Self-management tasks (e.g. self-monitoring blood/sugar managing a medication regime, managing a diet)	}	<b>Functional/interactive media/scientific/food, literacy skills (see sections 5.2, 5.6, 5.3, 5.5)</b>



### 6.2.3 Stage 3: health literacy actions

The third stage of the model represents **health literacy actions**; this is more active involvement in one's health and relates to *communication with health professionals* where a person is asking for a treatment or service, expressing concerns, bringing information to the health professional for further discussion. Interactive (person to person) health literacy is important at this stage of the model. Below are some examples of health literacy actions identified in this study.

#### Asking for a service

I did ask him if he could arrange for me to see an orthopaedic physiotherapist just for some exercise for the hip. (Participant 1CR)

Yes there's this new therapy called DBT which means dialectical behaviour therapy, it's quite new and it's supposed to have good results and I have spoken to my doctor about it and she feels that it's a good way to go and she's trying to arrange that for me.(Participant 2C)

#### Asking for a specific doctor

At one time I used to say look I ... is Dr X here, yes she'll say it will be years until she retires. I think oh she'll do she's the top one but uh she was always there that was the point. (Participant 2XP)

#### Asking for medication or treatment

I think it was sleeping tablets something like that which he didn't want to give me, and I insisted because I just wasn't sleeping and I was going out of my mind. (Participant 3CR)

I went and said "I need this drug it stops me from becoming anaemic, and my consultant has cleared it for a year so you need to give me more of it". (Participant 4CR)

#### Negotiating a treatment regime

I said "I'm not happy with the way things are going and I want to try something else" and I said "I want to try four injections a day I said instead of having two mixed in the morning have a mixed insulin and two at night I want three fast acting and slow for the night and try a completely different."  
(Participant 2XP)

#### 6.2.4: Stage 4: production of informed options

The fourth stage of the model represents the **production of informed options**.

There were two categories of options here, those produced by the participants from their engagement with relevant information and discussions with friends and family, and those presented in healthcare consultations by the health professional patients.

Here are some examples of informed options produced by participants: participant 4CR has used her skills in seeking and interpreting information to identify a potential alternative medication for anaemia (stages 2-4), participant 2XP also sought an alternative medication with the help of her husband's skills in searching for information online (stage 2) and discussions with a diabetes nurse (stage 3). She also had ideas about how her insulin injections were working on her body and thought about a new insulin regime, which she discussed with her doctor before making an informed decision to switch to this new regime (stages 3-5). Participant 4EP was unhappy with the side effects she was experiencing from taking statins; she had knowledge of nutrition and alternative therapies and researched other options which she then discussed with her GP (stages 1-4). She decided to try an alternative remedy (plant sterol) to lower her cholesterol (stage 5). These participants were able to seek out choices that had otherwise not been presented to them. Their individual functional health literacy, interactive person to person health literacy, media health literacy and access to another person with the necessary health literacy skills facilitated their progress along the pathway.

I did some research and I found a liquid aspartame that I can buy from Boots and she went OK. She had a look at it and discovered it only gives you a normal dose of iron and I need like loads so she said well there is another liquid form it's like a juice and I'm still taking that about three months later and that's had no side effects. (Participant 4CR)

I did think about going on a recent drug um called Byetta, it's quite new and I said could you have a look on the internet to see what they say about it and um I could perhaps ask my doctor then whether it would be suitable for me which is what we did yesterday but a fortnight ago I got in touch with the nurse. The nurse is my first contact and of course a couple of days later she sends me the information but he also printed it off the internet as well. (Participant 2XP)

On one occasion um having read the um flyer and tried the medication for a long time um eventually just decided to give it up because I just couldn't cope with the side effects and I found an alternative which is a plant compound plant sterols which I'm not sure at the moment whether they work effectively I'll know when I have a blood test this week um but uh I do read and then try to find a substitute for something if it's possible because the side effects were such that you know I just couldn't cope with it I had such pain in my legs morning ,noon, and night I thought you know I can't cope with this. (Participant 4EP)

Health professionals also presented options for participants to consider. For example participant 2XP was offered the option of using patches in place of oral medication for pain relief and participant 5EP was informed of options to treat her bladder problems:

He said well you can have a pain medication in a patch you just put on once a week and um I said oh well what's the difference you know? He said well you won't get the side effects that you are getting with the tablets I'm taking and they weren't very nice. I never liked them anyway, uh but I tolerated them and um he said you might find this a lot better once you've sort of changed over gradually from one to the other so um I didn't know what to think at the time so he said well go home and have a think about it, have a look on the internet he said you will be able to find all the information you want have a read about it he said and you come back in a month and then you know if you want to try it.  
(Participant 2XP)

I've been on tablets to try and help with the bladder and they weren't working they weren't really doing anything so we discussed coming off it and leaving me off the medication which we did and then I saw the MS nurse who suggested oh well let's try Fybogel it's to do with your bowels maybe that's causing all the problems and then we've also discussed the fact that if my next scan shows that I'm not working my bladder then I might have to have a catheter and those sort of things so I have discussed options in the past and I've been given information about the catheter and things like that and things to weigh up.  
(Participant 5EP)

Whether options have been produced by a patient or presented by a health professional, there is some appraisal of these options before a firm decision is made. In order to consider and appraise options it is sometimes necessary to access further information to build on existing knowledge and produce more options. Therefore, there is some feedback between informed options, health literacy skills and health knowledge.

### 6.2.5 Stage 5: making informed decisions/participating in shared decision- making

The fifth and final stage in the pathway model is **making an informed decision**; this is the stage where firm decisions are made about treatments or self-management tasks. For example, after learning about (stage 1) and carrying out research (stage 2) on self-monitoring devices for monitoring INR, participant 4 CR has thought about ways to obtain a device (stage 3), considered her options (stage 4) to acquire funding for a device to help her manage her warfarin medication, she entered discussions with health service providers and charities to negotiate funding for the device and the strips to use with the device (stage 3). After some negotiation with her primary care service she made a decision (stage 5) to buy the device herself and obtained funding for the strips from her GP surgery (stage 3). Thus, her decision is a result of acquired knowledge, skills in accessing and acting on information, consideration of available funding options and negotiations with health professional and charity organisations.

I will be monitoring myself and getting a coagu check machine which is like a blood like a diabetes machine which a charity is sponsoring me to have and which makes life so much easier.

I went in to ask for funding for my self-tester and they didn't have the funding, they referred me to a charity that could help and I got in touch with the charity and the charity were going to fund me but they didn't have money either. So they were trying to be helpful but at the end of the day I bought my own tester but the doctor has said that she can prescribe the test strips on prescription so that's taken away the burden of £150 every six months or so. (Participant 4CR)

Participant 4CR also made a shared decision with her GP about medication for anaemia: after researching options (stages 1-4) she discussed these with her GP (stage 3) who then recommended another suitable option (stage 4), she then made a decision to change to the recommended option (stage 5). Her skills in functional and interactive health literacy were integral to her decision making experience. In both cases the concept of choices was not presented to her, her initial options were a result of her own enquiry. Thus her opportunity for decision making was an indirect outcome of her health literacy abilities.

I got anaemic about two months ago and I had to go on iron, I have been on iron before I had the tablets at Christmas they made me incredibly constipated and I feel rubbish and so I went back to my doctor and said I really don't want to be on the tablets and I did some research and I found a liquid aspartame that I can buy from Boots and she went ok she had a look at it and discovered it only gives you a normal dose of iron and I need like loads so she said well there is another liquid form it's like a juice and I'm still taking that about three months later and that's had no side effects so don't have any nasty bowel stuff with it. It's a lot better so I do feel good sometimes. (Participant 4CR)

In the following two cases choices were presented to the participants, and decisions were made after some engagement with information and discussions with others. Participant 3CR was asked to make a decision about surgery on a carotid artery, she knew a bit about the procedure from talking to two friends who had had it done (stage1) and had a discussion with her daughter who had obtained information about the risks and benefits from the internet (stages 2&3). Following a discussion with her consultant at the vascular clinic she was confused about her choices and not ready to make the decision, she returned to her GP for further information and advice (stages 3&4) before making a firm decision to go ahead with the surgery (stage 5).

...you like then as an example when I had to have this done. The carotid artery done, when I went in.... this is around about but I'm getting there... when I went into the vascular clinic um I'd gone in once before when they had to see how it was going on and then when I went back then again in 2 months he said you must.... You need to have it done but it's up to you and they gave me the chance to take the decision. Which at the time I wasn't I really thought that they had done the you know that they had done you know the scans and everything I did think that surely if they thought that they wanted to ask me to make that decision they must have thought somewhere along the line I needed to have it done. Anyway they wouldn't do it unless I said yes or no and I... in that instance I actually said I need to go back to my doctor because, as I said, I trust him and I went back to my doctor. Now um he almost said the same thing oh come now you have got to think about this um but he... I can't explain it now it's some couple of months ago but he sort of put it in a different way um and of course the benefits were going to outweigh whatever risks.

As it happened, when I came home to think about it from the doctor's my daughter actually went on the internet and found out more about it and as well as anybody else she was saying well it says on the internet the benefits outweigh the risks.

(Participant 3CR)

Participant 5CR reflected on a past decision to take statins to help lower his cholesterol level; he talked about having existing knowledge of statins and potential side effects (stages 1&2), and entered discussions with his GP about going onto the medication (stage 3), leading to consideration of his options (stage 4) and his decision not to begin taking statins (stage 5). He also made a decision with his GP to take beta-blockers partly based on some discussion between them and his existing knowledge of medications.

We discussed the use of statins because my cholesterol was a little bit high um and um we talked about it jointly really and he said he wasn't..... he said he could put me put me on statins but he asked me what I felt about it basically and at that stage I said no um but only after discussing it not just a straight no.

When I first went on to beta-blockers for high blood pressure I kind of discussed it with the doctor and you know we decided.... I took his advice basically but I was aware that there was a variety of different medications. (Participant 5CR)

#### 6.2.6 Health literacy as a process and an outcome

The model devised here suggests that health literacy develops across time and within different health contexts. Thus, health literacy is as much a *process* as it is an *outcome*. Health literacy processes are represented in the five stages of the Pathway Model and the outcomes are represented as running parallel to those stages.

#### 6.2.7 Health literacy outcomes in the model

Although some participants in some circumstances developed their knowledge and skills in order to have a better understanding, skills to manage their condition and ways of coping with it, in other circumstances some were more active as patients and were motivated to use that information to identify options for treatment and care and enter active discussions with health professionals. This is represented as health literacy outcomes in the second level of the Pathway Model (figure 6.1); these are two broad sets of competencies that participants were able to achieve from their health literacy *skills*. These competencies were direct outcomes of stages in the first level: stages 1-3 were directly related to: a) increased knowledge and understanding of how to manage and cope with condition. There was an overlap where stages 3-5 related directly to b) being active and involved in consultations. Progression from knowledge

and understanding to active involvement was determined by advanced health literacy skills and motivations and facilitators along the pathway to informed decision making.

All participants had some health literacy skills that would achieve competencies related to a) increased knowledge and understanding of how to manage and cope with their condition, whilst others had more advanced health literacy abilities that enabled them to also achieve both a) and b) active involvement in consultations.

Here are some examples of participants who fitted into these two sets:

**A) Increased knowledge and understanding of how to manage and cope with condition**

Participant 1XP was quite knowledgeable about diabetes and was good at self-managing it. He engaged with lots of written information about diabetes provided in the media and provided by Diabetes UK. He monitored his blood sugar several times a day and kept a record of it, he felt he had good control over his blood sugar and was adherent to the medication regimes that were prescribed by his GP. He tended to be more compliant and was not particularly active in healthcare consultations.

**Both A) Increased knowledge and understanding of how to manage and cope with condition and B) Active involvement in consultations**

Participant 4CR actively sought information online and learned about her condition from internet sources such as charities and support groups in addition to her interactions with multiple health professionals. She built up an understanding of her condition and how to manage it over time and was very active in seeking alternative medications and self-monitoring materials that she required. She managed a series of appointments with a number of health professionals and specialists in her condition.

Participant 2XP also appeared to be competent in these two sets, she had developed an understanding of diabetes through interactions with health professionals, membership of Diabetes UK and engagement with information that her husband would look up online for her. She had skills in self-managing her condition but also strived to manage it better and sought alternative medications that might help her bring her

blood sugars down further. She actively engaged in consultations with health professionals.

Participant 4EP, 5EP, 1C and 4C were also quite knowledgeable about their condition, had skills in self-managing, and were actively involved in information seeking and exchanging information in healthcare consultations.

### 6.3 Section 2: Influences on progression along the pathway

There were three broad factors that influenced progression through the stages in the pathway; these were personal motivations, facilitators and emotional factors.

These are represented in the model with an arrow pointing along the pathway.

#### 6.3.1 Personal motivations

Some specific factors that motivated individuals to move along the pathway, and these were mostly associated with reasons for seeking and engaging with information.

##### *Understand symptoms and diagnosis*

Some were motivated to engage with information in order to help explain the way they were feeling and to understand symptoms and effects of medication. Sometimes this would involve engaging with information provided with medication, seeking information online and/or approaching a health professional to ask questions. Below are some examples:

##### **Symptoms and side effects of surgery or medication**

I read a book recently it was called um depression the illness of the strong or something and um in the front of the book he listed he told the reader what kind of qualities you hold dear and it was the first time I have read something and I thought that's me. I'll bring it next week it's only a little book but due to the way I feel about things with the things that I had experienced it was inevitable. You just work too hard and you work yourself to a breakdown basically. (Participant 1EP)

##### **Diagnosis**

I'd read books and there was books I'd bought and they were telling me there's eight questions or eight areas and if you've got five of them you are classed as manic depressive. (Participant 1EP)



### *Seeking options*

Another motivating factor in accessing and engaging with health information is to seek alternative treatment options. This was mostly due to experiencing undesirable side effects. The participant would then seek alternative options themselves and once they had engaged with information they would then produce options which they might discuss with a health professional before making the decision to change. Below are examples of two participants who were motivated to seek options.

I wasn't getting good readings at all and um I was looking for other options and she actually she actually got me into my diabetes doctor at the hospital oh on the third week of the course because that's when it all started I said I'm not happy with the way things are going and I want to try something else and I said I want to try four injections a day I said instead of having two mixed in the morning have a mixed insulin and two at night I want three fast acting and slow for the night and try a completely different. (Participant XP)

### *To be prepared*

Participant 5EP was motivated to engage in information seeking in order to be mentally prepared for the potential effects of her condition and to understand what her prognosis may be. Although some of the information was upsetting she was still interested in learning more. She felt that if she knew the potential effects of her condition and how to deal with them, it would make things easier for her to cope with. Thus, she was building up knowledge and skills that were appropriate to deal with potential difficulties associated with her condition, whilst at the same time limiting her emotional reaction to the effects should they occur.

I'm doing a lot of research at the moment into um what my condition is and what to look out for..  
..... I think it is very important because you need to know what's going to happen you need to know what to expect um even though those things might not happen. I think it's very important to at least know or have an idea of what could possibly happen otherwise if you don't you are just sitting in a ... your oblivious world and then when it does happen it can hit you twice as hard.

I know some people don't always want to know but I just think sometimes it's harder if you don't know I mean you suddenly find out it can make your recovery a bit harder in a way.

(Participant 5EP)

### *6.3.2 Emotional factors*

Emotional factors sometimes motivated participants to engage with information resources. In some cases there appeared to be a relationship between heightened emotions and a need for information. Some wanted to engage with information in order to reduce their fears and anxiety about their condition and to cope or 'put their mind at rest'. This was especially prevalent in the cardiac rehabilitation group; all participants had found the experience of being told about their need for surgery to be a traumatic event. Some participants talked about a relationship between understanding what needed to be done (in terms of surgery) and not being afraid.

I think if you didn't understand it you would be frightened of it all wouldn't you.... the more you know the better you are able to cope

(Participant 3CR)

As I learned more about what they do other ways that if I don't get on with them I can have different drugs, why they are working and how necessary it is.... it becomes less scary and it just becomes normal. (Participant 4CR)

Some participants wanted to build their knowledge of surgical procedures in order to make sense of their condition and to move on with their lives, it was viewed by them as part of their rehabilitation process. Participant 4CR sought information online to reduce her anxiety about the physical effects of her surgery and discussed them with members of an online forum in addition to her healthcare team. She also engaged with the media to view television documentaries and You Tube clips of the same surgical procedures that had been performed on her. She did this in order to reduce her anxieties about her insides being moved around during surgery.

It also helped her make sense of some of the effects of by-pass surgery and reduce her anxieties about them.

I had to watch it to put my mind at rest. I had to see everything that had happened so I can understand. I had questions about you know well I went to have my scan and they said everything is stitched back in place so there's obviously you've got bits that could move and blood could be lost. All of these silly little things go through your mind and then until you actually see how they stitch the valves in place and they just caught and it goes into place and how they tug it around to make sure it's secure and how they test it afterwards. Only then I was like ok I'll chill out now I know that it's safe and it's secure and I'm not going to leak blood everywhere and I'm not... nothing is going to happen and they got this

woman up a couple of days later who looked exactly the same as me and she went through the whole same process so it was really... that was another turning point I watched a few surgeries on You Tube as well in kind of... not in a morbid sense but I needed to see what happened.

(Participant 4CR, interview 3)

### 6.3.3 Facilitators

#### *Distributed health literacy skills amongst friends and family*

Progression along the pathway was not always an individual task; some participants received the support of others to progress through some or all of the stages. Some participants used other people's health literacy skills as a resource to help them seek, understand and use health information to help manage their own health and/or make informed choices. Health literacy was distributed amongst family and friendship networks, in some instances participants sought support from others that helped them progress through the stages on the pathway and sometimes friends and family would naturally intervene and offer their support and skills.

Knowledge was shared and passed on by friends and family, who used their health literacy skills to help access information for the participant and to interpret and analyse that information. Friends and family also communicated with health professionals on behalf of, and in collaboration with participants and supported them in their health literacy actions. They sometimes co-produced options with participants by supporting them to seek and use information to consider treatment options or behaviour and lifestyle changes, and they influenced and supported their decision making.

Distributed health literacy was useful to some at various points on the pathway and helpful in isolated areas where participants needed the support of others. Thus, some had skills and knowledge, that enabled them to act more individually. However, some participants received the support of others all along the pathway. For example participant 2XP was inexperienced in using a computer to seek health information and her husband helped her seek new alternative medications online, they discussed the information between themselves, with people they knew who were taking it, and with their practice nurse and GP before making the decision to try out the medication.

I don't use the computer personally but I get my husband to do it so if I want to know anything I get him to have a look on the internet and print something out that I'm particularly interested in. I did think about going on a recent drug um called Byetta, it's quite new and I said could you have a look on the internet to see what they say about it and um I could perhaps ask my doctor then whether it would be suitable for me which is what we did yesterday.

Yes he met somebody who tried it (Byetta) and said it was wonderful but I think it affects you know individuals differently um it obviously worked for this woman but um I think he was more keen for me to try it than I was.. But I thought I would give it a try he (husband) was keen on it and I almost had to sort of um beg him(GP) to give it to me because he wasn't happy, he didn't particularly like the drug. But like I said you know you can try it, it won't hurt. (Participant 2XP)

Participant 3XP had computer skills and was able to search for information, however she encouraged her husband to seek information too because she thought that he was more analytical than her. She drew on her husband's interactive media health literacy skills at stage 2 in the model and thus both their health literacy skills would contribute towards considering informed options and decisions about treatment and self-management.

If I want to know something I will ask him to look it up on the internet for me simply to get him to be aware you know and it's not that I'm not capable of finding things for myself but if I ask him to do it he will look into it and he's very analytical. (Participant 3XP)

Participant 5EP lives alone and has particular difficulties that mean she needs support at home. Currently this is provided by her mother who calls on her daily. Her brother looks up information online and discusses it with her and her mother. He does this so that the family can have a shared understanding of her symptoms and difficulties and also to look into what her prognosis is likely to be. Her family engage with health information to find ways they can provide care for her and help her live independently in her home. Thus, knowledge of her condition, skills in researching information and care responsibilities are distributed amongst the family and were used in stage one, two and three of the model (health knowledge, health literacy skills and health literacy actions).

I learned from my brother, he phoned my mum the other day they said in some cases it can take up to 4 years to recover and in terms of how people have coped with that um and he was trying to explain to my mum it could be a while you know it's not going to happen overnight because I think my mum's quite ... and he's trying to say you know people do recover and things like that. So I know my brother has shared with her from looking at things on the internet. (Participant 5EP)

Participant 3CR was given a choice on whether to have surgery on her damaged carotid artery by her consultant at the vascular clinic. Given that she was also unable to use a computer very well; her daughter used the internet to seek information on the risks and benefits of the surgery. Thus, her daughter was able to use her computer literacy skills to access information in order to support her mother in considering her options and making a decision on whether to have the surgery.

My daughter actually went on the internet and found out more about it and as well as anybody else she was saying well it says on the internet the benefits outweigh the risks um. (Participant 3CR)

Some participants received support from family or friends when communicating with health professionals. This was sometimes due to the nature of the information and the complexity or amount of information that needed to be discussed or because the timing of the information was at a particular time when the participant felt stressed or anxious about their diagnosis. Participant 1CR had problems taking in information from her consultant about why she needed to have an angiogram; she was shocked and found it difficult to process the information. Therefore she asked the consultant to explain things to her relatives, who then could talk to her about it. Participant 5EP also talks about sometimes having problems processing information in consultations and takes her mother or partner but also takes a friend with a health service background to draw on her knowledge and critical skills.

He explained it to (partner) and to (brother) and then they explained it to me and that was fine that's all I wanted. (Participant 1CR)

I have someone with me I always have someone with me. My mum normally comes with me um and my partner comes with me. (Participant 5EP)

I always have someone with me I even from working in the health profession I was always taught if you are going to see a doctor have someone with you because you don't always process what's been said um so it's good to have that person with you. I've got a friend who has an NHS background who sits there with me because there are certain things she's questioning as well so yeah and I think also for my own piece of mind just to process everything as well. (Participant 5EP)

The parents of participant 4CR were present at the hospital when she was communicating with health professionals. They took notes for her to help her reflect on what was said because she found it difficult to take in the information due to the seriousness of her condition and the amount of anxiety it caused her.

My parents are really good as well they um...they've done a lot with my grandma who is quite ill and they learned very quickly they need to write things down so every time I had ward rounds and I have 4 or 5 a day and every time I've gone for an appointment ...I don't do it myself but whoever is with me will write things down. And so we can remember what they've actually said because I never remember and when you are there and they are saying really scary things you don't remember.

#### *6.3.4 Supportive health professionals*

Supportive health professionals facilitated the development of health literacy. Some did this by encouraging participants to engage with information before making a decision about a change of treatment option. For example, participant 2XP was informed of the use of patches for pain relief by her GP and asked if she would consider them as a convenient treatment option. He then suggested she look at the information about patches that was available on the internet. She went home and, with the help of her husband, looked up the information. She assimilated the information that she had received from the GP and had read online and made an informed choice about changing from an oral treatment to a patch method. In this scenario the health professional supported the participant in her engagement with information to make an informed choice.

He said well you can have a pain medication in a patch you just put on once a week and um I said oh well what's the difference you know? He said well you won't get the side effects that you are getting with the tablets I'm taking and they weren't very nice. ....he said well go home and have a think about it, have a look on the internet he said you will be able to find all the information you want have a read about it he said and you come back in a month and then you know if you want to try it. (Participant 2XP)

In some cases health professionals responded to patients' health literacy abilities. In turn, participants benefited from having access to more knowledge about their condition and were potentially better able to manage their condition or make informed choices about their treatment options. For example three participants (4CR, 4EP, 5CR and 5EP) appeared to show more advanced health literacy and have good interactive health literacy skills. They felt that they were able to access additional information from health professionals and health professionals were very responsive to their level of knowledge and understanding so there was less need for detailed explanations.

I think they know me quite well and they know how I usually respond to them and their questions and that I can talk at the same level as they if they wanted me to do that I can understand medical technology they don't have to explain everything to me. (Participant 5EP)

My doctor is really good. You know even if for example if we are talking about blood pressure or cholesterol levels or whatever he'll turn the monitor around of his computer and actually go through what the figures are and things like that you know so you know nothing is hidden and he'll tell you what your blood pressure is each time he takes it and he'll tell you. (Participant 5CR)

In some cases health professionals sought information to help build both their own and the patient's knowledge. Participant 5EP had an MS (multiple sclerosis) nurse who would look online for information and answers to some of her questions. She had also developed a good relationship with her GP since developing her condition and feels that her GP knows her well and is interested in her life within the context of living with a condition and the difficulties that she experiences. Her GP also assisted her in seeking information. Participant 4C also experienced a similar relationship with her GP in managing her asthma and allergy condition. The relationship that both these participants have with their GP and their GP's patient-centred approach helped facilitate the development of health literacy through an exchange of information, support in seeking information and guidance on what to do with that information in terms of self-management decisions.

**Support information seeking**

Um he has been quite good and in terms of if there was anything I wanted to know he would try and find out. He was good in assessing my medication um we've discussed many times altering some of the medication if something isn't working and he's like informative and quite good and I will ask questions he's been quite good about going and trying to get that information for me if he didn't have an answer to it. (Participant 5EP)

Yes I read about salt pipes being very good, it's literally like a clay pipe and that sort of thing and you literally sort of have to inhale it. I've got a friend up north and she has got her son on it after reading about it and I was a bit more sceptical about it and I discussed it with the GP and he didn't think besides it might overload your salt intake. He didn't think there is much clinical evidence of it and to be fair to him he went off and researched and the next time I went back he had allsorts of different studies that he had printed off to read about it more , that's because I think he's interested in all that area. (Participant 4C)

**Health professional focus on person (patient centred)**

So he's quite good I've gotten more answers from him because my consultant said I can go back to work and my GP was like no way and he said no you won't be going back to work for a long time and that's what made me very angry with the consultant who didn't know my case. Where the GP knows me more and he made a decision in terms of he discussed with me looking at another 18 months until I can even think about going to work. We talked about... I'm still waiting to see a neuropsychologist and I feel like my brain is slowly dying, I'm not having any sort of stimulation in terms of studying or working so we talked about an Open University course we talked about how we could... that could be viewed as brain rehab and rehab for my brain could be a really good thing because it tests how far I can go. (Participant 4EP)

He realises that I work full-time, I've got all other things going on so he seems to have that... he thinks my job is a ridiculous job because it is nights and weekends and bank holidays as well as Monday to Friday. So he is... yes, he sort of takes all that into consideration really and he'll ask me what I'm doing work-wise if I am poorly or.. and he's aware when I've been in there because I've been really sick and need operations he's aware how that can make you feel really and sort of extra stresses. (Participant 4C)



*Pharmacist support*

Some participants talked about support they had received from their pharmacist. Pharmacists provided participants with information about their medications and supported them in managing their medication regime. Consultations and discussions with pharmacists facilitated the development of health knowledge (stage 1) and health literacy skills (e.g. managing a medication regime) (stage 2) and provided participants with information they could then discuss further with their GP (stage 3).

I have to have my meds pre-packed and I had a pharmacy review of my drugs when I first had all my drugs renewed and we sat down and he went through everything with me made sure I was having... I even had the pharmacist at the hospital phone me to double check I was having blood tests regularly and ask if everything had been explained to me and they double checked that um and Boots pharmacy phone me once a month to check what drugs I need ordered and to check what I need packed and when it needs to be packed so I found that very good. (Participant 5EP)

They keep a check on the changes, how you are coping with the um... do you feel like you are getting weaker or stronger you know that sort of thing.....The pharmacist down there is quite happy to talk at any time that is convenient for you really. Which is quite good, I mean not all pharmacies are like that. (Participant 2C)

*Nurse support*

Almost all of the participants talked of support they had received from contact with a nurse. These were hospital nurses, community nurses, diabetes specialist nurses or practice nurses. Participants in the diabetes group commented on the support that was provided from their practice nurses. Their practice nurse was often the first point of contact for these patients and also their main information provider. Practice nurses sometimes assisted in seeking medication options with a participant and informed and supported transitions to new medication regimes. Practice nurses also facilitated access to further information and other health services needed to support people with diabetes. Nurses helped facilitate progression between stages by helping participants increase their medication knowledge (stage 1) teaching participants self-management skills (stage 2), facilitating access to other services and communication between participants and doctors and introducing treatment options (stage 4).

So she looked at other new types of medication. I said “yeah I’ve tried that one and I’ve tried that one and that one”. She said “really the only thing left is for you to go on insulin and how do you feel about that”. I said “if it works without the side effects great I don’t mind the injections”. And of course when you go on to insulin the nurses are there to show you to do it and show you how to cope so you’ve got the help once you get to that level. (Participant 2XP)

The nurse is my first contact and of course a couple of days later she sends me the information.  
(Participant 2XP)

Um the nurse at the practice who’s leaving uh gave me the number of the diabetic clinic at the hospital and said ring the hospital and go to them. (Participant 3XP)

Participants in the cardiac rehabilitation group talked about the information and support provided to them by nurses at the hospital. Two participants talked about the nurses explaining to them what was happening and helping them understand the processes that they were to undergo or had already been through in relation to their surgery or their rehabilitation.

To begin with uh one of the nurses she was great and I can’t remember her name. But she sort of explained after because I was a bit disturbed because it took me too long to come out of the anaesthetic because this time I had anaesthetic and I asked the surgeon and he said well he said all I can say is that it’s a cocktail of drugs and one of them might be...he said we were a bit you know not really really worried but a bit concerned. So I was talking to this nurse and she explained what they did I said I don’t want to know all the details but she did explain. (Participant 1CR)

They go to great pains to make sure you understand what’s happening. Um so I went down to the operation... I’ve always said I’d go shouting and screaming to an operation um well I went down quite happily. Ignorance is bliss I suppose in a way and then afterwards I think. I think all along the lines somebody is helping you to understand what is happening. (Participant 2CR)

Participant 2C receives support from her community psychiatric nurse; she tends to help her manage her condition and works with her to feed back her well-being to her consultant psychiatrist.

Yes, she visits me every week to make sure I’m ok, to make sure I’m taking my meds. You know keep me up to date and then sort be the go-between between me and my um consultant as well.  
(Participant 2C)

### ***6.4 Section 3) Barriers to progression along the pathway***

There were several barriers that prevented or delayed progression along the pathway and inhibited the development of health literacy skills and opportunities for participants to become actively involved in healthcare consultations.

These barriers are broadly categorised as professional barriers, personal barriers and emotional barriers. Barriers are represented in the model by a left-facing arrow.

#### ***6.4.1 Health professionals***

There were several areas where health professionals presented barriers to the development of health literacy and progression through the stages in the model. These involved poor communication, barriers to accessing information and a focus on disease more than a focus on the person.

##### ***Poor Communication***

Difficulties in communication between health professionals and patients were a barrier to progression from one stage to another and both hampered the development of health literacy skills and undermined the opportunity for participants to make use of their interactive health literacy skills. Insufficient information contributed to gaps in participants' knowledge and left them to their own devices in trying to understand their condition and how to manage it. Some had enough health literacy skills to access information, gain further knowledge and develop self-management skills and others needed the support of health professionals and health educators to help them develop their health literacy and self-management skills. Those with lower health literacy skills could have been more disadvantaged in consultations with health professionals who did not provide sufficient information, withheld information, or failed to listen and dismissed information that a participant brought into their consultation.

Sometimes health professionals provided poor information and did not communicate effectively with participants when informing them about their condition. Some participants specifically referred to 'not being given enough information' and 'not being listened to' about their condition in consultations.

When I first knew I had diabetes I didn't have very much information given to me from my doctor's clinic. (Participant 2XP)

I wasn't told anything. Uh the doctor gave me I could show you what it is he gave me a photostatted copy sheet off and he said you can't eat any of the stuff on this sheet....which is rubbish actually...I can (laughs). (Participant 2XP)

In some instances participants felt that information was not given because the health professional lacked knowledge of their condition or it was beyond their remit to provide information on certain issues to do with their condition.

My GP couldn't really give me an answer as he only knows a limited amount because when I went on to insulin when the other medication originally didn't work for me he said you are going to the hospital for that so I got out of his..... I only went up to his level so far, after that anybody on insulin didn't come under him he didn't look after that. (Participant 2XP)

Health professionals sometimes created a barrier to the development of health literacy skills by making incorrect assumptions of some participants' information needs and their ability to understand of health information. One health professional refused to give requested information to a patient on two separate occasions. Participant 3XP wanted to see her blood test results but her GP would not let her have her results, based on his assumption that she would not understand what they meant. She was insistent that she would understand or try to find out if she didn't understand but failed to obtain the information. On another occasion her GP did not offer information that she requested about swine flu. Her purpose for wanting the information was to make an informed decision whether it was safe for her to visit a relative after she had come into contact with a person who had swine flu. The GP had made a suggestion to her but had not answered her specific request for information. It may be that the GP chose to give her advice rather than information, and did not think that she needed to

know the incubation period was to make her decision. Nevertheless, her decision was not to go, based on not knowing whether it would be safe.

I've had terrible trouble getting out of him what my uh results are from the consultant at the hospital and um you know my blood results. Uh and his attitude was well you don't know what they mean so it's not. And I say yes but I do know what they mean and if I don't I will find out. He must think I'm a terrible person. Um and I he's very reluctant to give me my results and I have to say "well I need them I need to have them please can I have them." (Participant 3XP)

I went to see the doctor and I said "oh by the way could you give me the incubation period for swine flu". "Why"? So I explained and he said," if you are feeling ill don't go" and that was the reaction that I got. I didn't get any information from him. (Participant 3XP)

Some participants felt that information that they brought with them or ideas that they had about treatment were 'dismissed' by their health professionals. This created a barrier to both participants exchanging information (stage 3) with their health professional and undermined their level of interactive health literacy.

I attached to it a list of all the other medications and the supplements I was taking and sent it to him so he had it in good time before the next consultation, but I don't know he just didn't really acknowledge that I'd given him much information at all. (Participant 4EP)

He's very offish and very um when I asked him.... I said to him DR Y said... well that was then he was very dismissive especially about the baclofen and the medication for the stiffness. He was totally dismissive about it. (Participant 5EP)

Some participants talked about consultations being rushed. However, some had ways of overcoming the fact that their GP rushes information and they have not always fully taken in the information in the consultation. Participant 4EP asks for written information and participant 5EP uses the internet to clarify the information that her GP tends to rush through and then discusses it at a later point with her GP. With their opportunity to use their interactive health literacy compromised or delayed, they both use other functional and interactive media health literacy skills to engage with information and extend their knowledge and understanding.

I need to read up further or if they talk very quickly, because the consultation times are very short aren't they? They talk quickly and I haven't necessarily grasped it all. (Participant 4EP)

Consultants tend to rush through everything with you but on the internet you can take your time to digest it in and then you can take that information with you and you can go into your doctor next and ask him. (Participant 5EP)

### *Access barriers*

Health professionals can also sometimes create a barrier to a patient accessing other health services. For example, participant 2EP wanted to have psychological treatment for bipolar disorder rather than medication but felt that his doctor was not listening to him and did not refer him to a psychologist.

But going back to the doctor when I didn't want to take drugs I think personally that he should have listened to me and referred me to someone that could help me without going on the medication. (Participant 2EP)

### *A focus on disease*

Some participants talked about a health professional 'not interested in them as a person' and just treating their disease or disorder. Participant 5 EP talks about the consultant 'just seeing her brain'. The focus on her disease does not provide her with information and skills on how to live with the effects of her brain disorder and has contributed to her lack of confidence in her consultant. This relationship presented a barrier to someone developing interactive health literacy to a point where they can ask questions and exchange information about their condition within the context of their everyday lives.

Some people just think it's acceptable. A patient has a right to be treated as a person and it shouldn't be just the disease that's looked at. It should be you as a person as well because you need to know what's going on you need to know what to expect and it's alright talking about the disease but it's been very off putting for me that my consultant just sees the brain and doesn't see anything else he doesn't see me as a person and what I struggle through which has given me no confidence in him to be quite honest even though he may be a really good person in terms of treating MS and the disease he treats I don't have confidence in him as a doctor and I haven't from day one. (Participant 5EP)

*Conflicting or inaccurate advice*

In some instances participants were given two separate pieces of information or advice by two different health professionals. Sometimes the information and advice was not consistent or there was disagreement between the health professionals. Sometimes this would be due to one of the health professionals being incorrect and other times due to differences in professional opinion on a condition that is very rare. Conflicting information can be confusing for patients who must try to evaluate which advice to take on board. In the case of Participant 4XP, there was great feeling of disappointment after the practice nurse had disagreed with information given by her GP; this did not add to her knowledge or understanding of how to manage her diabetes. Participant 4XP had not engaged with much information about diabetes at this stage and had not developed her health literacy to a point where she could think critically about information and advice given to her.

I mean she did tell at the time which boosted me up no end that a lady had diabetes 2 and she said she slimmed right down and she went to have a check there was no diabetes there at all. Now when I went to the nurse then and we were talking about it and the nurse said "I know Dr Y has told me this as well but I don't believe it" and it knocked me for six a bit you know because ,you know Dr Y had sort of boosted me. (Participant 4XP)

Participant 5EP had a diagnosis for a rare brain disorder (Acute Disseminated Encephalomyelitis) which is similar to Multiple Sclerosis (MS). Her two initial consultants disagreed with her prognosis and whether her symptoms could be regarded as the same or similar to those of MS. This disagreement in professional opinion caused frustration and uncertainty for the participant, but also prevented her from accessing particular care services.

My first consultant said it was going towards MS and my second consultant won't commit to it. He was very much this is what I think it is now and he won't commit to it because although some things are positive my brain scan is not showing a typical picture so it's all very frustrating.

I've seen Dr X who totally contradicted what this other one had said and I still haven't seen a social worker and I still haven't seen an OT.

Participant 4CR had received different advice about managing her INR safely and her dosage of warfarin from her primary care team compared to that of her doctors at the hospital. The advice given by the primary care team was incorrect and put her at risk for some time. Although her trust in the medical profession led her to comply with the advice for some weeks, she had remembered what she had originally been told at the hospital and checked it with a nurse who took over the monitoring and arranged for the primary care team to be advised of the correct INR limits. As a physiotherapist participant 4CR was quite advanced in her health literacy and this helped her overcome the misinformation barrier.

I kept going back to the GP my to get INR done and was say 2.3, 2.1 it got to 2.0 and they told me to reduce my dose again and when I was in hospital my nurse told me my INR should be 2.5 to 3 and I thought if it is only 2.0 and I'm being told to reduce it... it got to 1.9, 1.8 for many weeks. I called my cardiology nurse and said "is this right" and she went "no, you definitely need to be above 2.5 you are a great risk... for the next few days and you are going to come here to have a test", and she got the surgeon to write to my doctors and say she definitely needs maintaining here. (Participant 4CR)

### *Overcoming barriers*

Some health professional barriers prevented the development of self-management skills and access to healthcare services. For example, inaccurate or conflicting advice, insufficient information and a focus on disease delayed some participants in learning how to self manage their condition. Furthermore, these same factors and non-referral to other services delayed or prevented access to further support from other healthcare providers such as nurses, occupational therapists and psychologists. Whilst some participants could overcome barriers such as insufficient or conflicting information by seeking their own information sources (stage 1), other barriers were more difficult to overcome. For example, barriers where health professionals prevented access to services and did not facilitate the production of options and informed decision-making (stage 5). All health professional barriers prevented participants' involvement in active discussions of options (stage 4) and decision making in consultations.



#### 6.4.2 Personal barriers

Some participants had personal barriers that prevented them from carrying out health actions such as accessing GP services or asking questions in consultations. Personal barriers tended to be based on attitudes towards health and help seeking behaviour. Personal barriers were mainly barriers to accessing services and accessing information from others and prevented progression to active involvement in healthcare consultations. These barriers were a lack of personal motivation, not accepting a diagnosis and a tendency to be compliant to medical advice.

##### *Lack of personal motivation*

Participant 3CR felt that she had to have a 'legitimate reason' to visit a doctor; she claimed not to be 'very curious'. Her attitude towards seeking help is a potential barrier to active involvement in health consultations.

I'm not very good at running to the doctor all the time you know. I've really got to feel I've got to be there (laughs). No... no perhaps I'm not very curious I don't know.  
(Participant 3CR)

Participant 3XP was unhappy with the service at her GP surgery but was apprehensive about making a complaint because she thought that she might experience negative repercussions. Her reluctance to complain was a personal barrier to becoming more actively involved in her care.

Yes I have thought about it and I think a lot of the problems now that you hear about these people who've sort of made complaints if you like and get banned from their surgery and banned from... can't get a doctor and so you sort of think hang on and hold back a bit you know. (Participant 3XP)

##### *Not accepting a diagnosis*

Participant 4XP had a problem accepting her diabetes; this affected her development of health literacy in a number of ways: she did not want to disclose her diabetes to other people; even people who she knows are diabetic. This prevented her extending her knowledge of diabetes and self-management skills through distributed health literacy.

I don't want to talk about it to people then you know. Yes I'm fine talking to you about it because you know about me but so many people don't. And yes other people understood how I felt I didn't think of it as a stigma but yeah I suppose some people do I just felt I'd never been ill in my life and I didn't want to be ill now and whenever anyone said to me like on the insurance and that no I'm perfectly fit nothing wrong with me. (Participant 4XP)

Her difficulties in coming to terms with the fact that she has diabetes also made her apprehensive about visiting her GP to review her blood sugar level. This behaviour prevented her from becoming actively involved in health consultations.

I don't really want to go to the doctors. I've got to go I know because I'm afraid of what they are going to say like you know. That it's gone worse or have this or.. I'm sort of putting it off all the time like you know. (Participant 4XP)

#### *Compliance to medical advice*

Some participants relied on health professionals as their only source of health information and engaged with little or no other health information. Although participants were happy to comply with medical instructions, it was a potential motivational barrier that limited their progression towards active involvement in healthcare consultations and inhibited their development of interactive health literacy skills.

Participant 1CR had strong views on not engaging with any other health information other than that provided by her doctor. She followed her doctor's advice on medications without further question.

I just listen to the doctor. I had all the medication when I came out of hospital. In matter of fact it was only last week I went to the doctor because of this pain in my arm which is caused apparently when they are operating on me um and I said have I got to take all these tablets all the time so I gave him the list that I had from the hospital and uh he did cut out one but otherwise, I got to keep the others on but otherwise 9 out of 10 times I accept what they tell me. (Participant 1CR)

I'm afraid I'm one of these people, I'm told to take tablets and I take them and that's it but I notice with other people they were asking questions and they really must read those leaflets that are inside the tablets inside the box that are very detailed... I don't. I'm given the tablet and I take them. (Participant 1CR)

Participant 3CR was also very compliant with medical advice; she had a lot of trust in the medical profession and was happy to take medication as advised with no further need for information.

I have great trust in my doctor uh so I do tend to think will...I know some people they tend to know everything about their medication and I forget the names or anything as far as I'm concerned I've got these boxes of medication and I take them because he said so. (Participant 3 CR)

#### *6.4.3 Emotional reactions*

Emotional reactions played a part in whether people wanted to or were able to comprehend information about their condition, or the details of procedures such as surgery. Fear and anxiety acted as an emotional barrier to engagement with information and access to services. This barrier was sometimes long-lasting and at other times temporary. Emotional barriers were mostly present between stage one (health knowledge) and two (health literacy skills) in the model and between two and three (health literacy actions) in the model. Those with emotional barriers tended to also remain in stage (a) of the health literacy outcomes. After moving from stage 1 (knowledge) to stage 2 (health literacy skills-seeking information) participants with emotional barriers tended not to progress, remaining in the a) increased knowledge and understanding of condition stage in level two of the model. Emotional barriers are depicted in the following extracts of data:

Participant 4CR found that some of the information that was available online on her rare heart condition was particularly distressing for her and her family to engage with. She decided to stop looking at it and encouraged her family to stop too. At that time she relied on the information provided to her by consultants at the hospital.

I try not to look too much. There's definitely a point which you say to yourself I need to stop looking now um before the operation I did put a clamp on it and told my family not to look because it's just scary the information out there and some of it's very wrong. (Participant 4CR)

After some time she was ready to engage with information again. She talked in a later interview about watching surgery on TV and online to learn about the surgical procedures she had undergone. Initially she had not been able to think about what her surgery entailed but as time passed she wanted to know what the surgeons had done. Where she was anxious at first of knowing such details, months later she was more anxious about not knowing the details and was ready to access the relevant information.

Yes something I found out afterwards and a good few months before I could even approach the subject and even begin to think about things as scary as that. (Participant 4CR)

Participant 1CR found it difficult to understand some of the information that her consultant was attempting to give her because she was temporarily shocked about needing by-pass surgery. Her anxiety prevented her from processing what the consultant was telling her. After the consultant explained to her family what was going to happen and her family reiterated it to her she was able to take the information in.

I must admit in the very beginning when the consultant told me I did. I was absolutely shocked. But fortunately my brother and my partner were in the ward and I said I'm sorry I just can't understand what you are saying because I'd never even thought about it. (Participant 1CR)

Participant 4XP was reluctant to visit her GP to review her blood sugar because she was anxious about what her results may show. Thus, her fears and anxieties associated with diabetes prevented her from accessing support from her GP.

I don't really want to go to the doctors. I've got to go I know because I'm afraid of what they are going to say like you know. That it's gone worse or have this or.. I'm sort of putting it off all the time like you know. (Participant 4XP)

#### *6.4.4 Poor mental health*

Some participants experienced mental health problems that prevented or delayed them in engaging with information and acting on it. For example, participant 2EP had depression and although he had engaged with self-help books on coping with depression, he felt too unwell to put the knowledge that he had obtained into practice. This is illustrated in the following interview extract:

**Participant 2EP:** It's alright reading these things and understanding them but actually when you are in a certain situation it's

**Interviewer:** Is it harder to put them into practice because of the way that you are feeling?

**Participant 2EP:** At the moment yes, although I know about these things I know it could help me there's something I don't know...there's something sort of stopping me through breaking the chain I suppose and getting on top and moving forward again.

**Interviewer:** So if I can get this right you understand what you can do and what might be helpful to you but because of more personal reasons it's difficult to put those into practice.

That's correct.

**And so if you felt better it might be easier for you to put them into practice.**

Yes

In this extract the student needed to probe more, this is because the participant seemed to be embarrassed and had problems expressing his thoughts. Hence, the researcher wanted to help him clarify them and show an empathetic understanding of how he felt about using health information.

Participant 2C had borderline "personality disorder" and had some knowledge about her disorder and available treatment. However, when unwell she has experienced problems expressing the way she feels to health professionals. Her poor mental health is therefore a barrier to active involvement in consultations. She also limited her contact with other people with mental health problems because she doesn't want to take part in sharing experiences. Her concern was that listening to other people who are depressed would not be beneficial to her own mental health. This was a potential barrier to learning self-management and coping techniques from others. She also limited her engagement with information on the side effects of her medication, which could be a potential barrier to successful self management.

**Communicating with health professionals**

The only problem is that sometimes you feel so low that you can't talk to anybody, even though you want to. It's like you become locked in your mood you know. It's like having a pain. Everything else is sort of pushed way back, all you can feel is the pain.

**Support groups**

I mean it is nice to have people understand but you know when they are talking about their depression or their mood swings or whatever, it can become too much for you to handle their problems as well as your own.

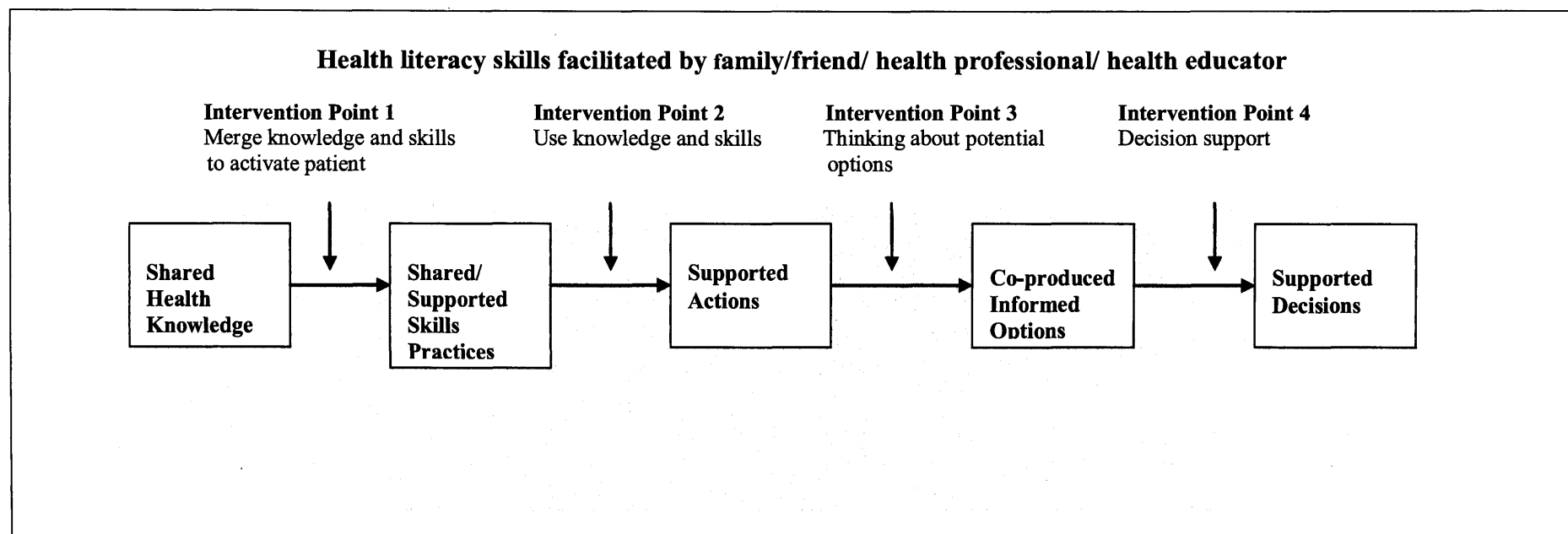
It's kind of like if you have got cancer or if you have had your legs amputated you know it's there you don't want to be reminded every time of that kind of negative things. It's hard enough trying to cope with it without constantly being bombarded with information and people being sorry for you and stuff like that. It can be in itself a negative thing. That's what I feel anyway.

(All participant 2C)

**6.5 Potential intervention points along the health literacy pathway**

Individual health literacy related abilities included in the five stages were supported by shared abilities held by those who influenced progression through the stages. Potential intervention points occurred naturally in a number of health contexts (e.g. home, work-place, healthcare settings). Those who provided intervention at these points were friends, family, health professionals and health educators. Figure 6.2 below shows potential intervention points in the stages of the pathway model, at intervention point one new knowledge and skills are developed, at intervention point two knowledge and skills could be put into use to support and motivate the participant become more active in consultations. At intervention point three participants could be supported to aid thinking about different options or new options that may have been presented to them and at intervention point four participants could be supported in their decision-making. These intervention points are explored within the context of patient education in the next Chapter in Figure 7.1.

**Figure 6.2 Potential intervention points along the health literacy pathway**



## 6.6 Chapter summary

This chapter has presented a new understanding of how health literacy may develop for patients with a long-term health condition. The Pathway Model was devised based on an analysis and interpretation of participants interview responses and provides an explanation of five stages that people may progress through in order to become informed decision makers in their health care. Health literacy is represented in the model as both a *process* and an *outcome*. Initially, patients require health knowledge (stage 1) and then from that they may develop health literacy skills and practices (stage 2) (these may be self-management skills and practices, and information seeking skills and practices).

The outcome of knowledge, skills, practices and actions in the first two stages may be an increased knowledge about one's condition and an understanding of how to manage it. From building knowledge and skills, people may choose to become active within healthcare consultations. This behaviour is represented in the model as health literacy actions (stage 3) and relates to situations where health literacy is put into practice in order to ask for services and treatments. Some people may have enough knowledge and skills and may have participated in health literacy actions that have provided them with a further ability, that is the ability to seek and put forward their own treatment options in consultations with healthcare professionals (stage 4). The fifth stage in the model explains how people may have increased their knowledge and health literacy to a level where they are most likely to participate in making an informed decision or participate in shared decision-making. The outcome of stages three, four and five in the model is more active involvement in consultations.

Participants talked about factors that present barriers to progressing through the stages in the model. Some barriers were personal to the participant and were related to emotion (e.g. fear), poor mental health and acceptance of diagnosis, and some barriers were created by the attitude and behaviour of health professionals who sometimes had poor communication styles and did not support patient involvement in information seeking and decision-making.



There were also factors that helped participants move through the stages. Emotion was an important factor in people developing skills in information seeking; personal motivations helped people progress and health professionals who were supportive of information seeking and patient choice facilitated the development through the stages.

As will be seen in the succeeding chapter, some patient education programmes also facilitated progression through the stages in the model by providing new knowledge and encouraging the development of self-management skills and active involvement in consultations. The role of patient education in developing health literacy and the learning methods that facilitate health literacy development will now be discussed in more detail in the following chapter.

## **7.0 Development of health literacy in health education contexts**

Chapter five introduced eleven categories of health literacy that were identified in this study and explained how they were practiced by participants in the management of their long-term condition. Chapter six explained how health literacy was developed and identified barriers and facilitators that affect the development of health literacy and informed decision making. This chapter will explain the development of health literacy skills through disease-specific and self-management patient education programmes. The aim of the chapter is to answer the research questions: (6) can health literacy be developed better through group-based patient education programmes and (7) what social interactions are involved. The research evidence for this chapter comes from the participant observation that was carried out in the three programmes (Cardiac Rehabilitation, X-PERT Diabetes, and Expert Patient Programme) and interview responses from participants.

The chapter is separated into four parts:

- *Distributed Health Literacy in Patient Education Classes* – Detailing how participants share information through discussing experiences and passing on advice to others within the class.
- *The Development of Health Literacy through Formal Learning* – Describing how the delivery of the programme helped develop skills in some categories of health literacy described throughout this thesis.
- *Informal learning opportunities* – Describing how informal discussions with programme tutors helped facilitate health literacy development.
- *The Development of Health Literacy Categories in Patient Education Programmes and Intervention Points in the Pathway Model* – Explaining how distributed health literacy, formal learning through taught elements of the programme and informal learning opportunities act as interventions that help participants progress through the stages in the health literacy Pathway Model (see figure 6.1 in chapter 6) and help some participants overcome barriers to their health literacy development.

## **7.1 Part One – The spread of distributed health literacy in patient education classes**

### **7.1.1 Distributed health literacy, social cohesion and social capital in the X-PERT diabetes programme.**

#### *The Programme Setting*

The X-PERT class took place at 1.30pm on Mondays in a village church hall.

There was one course tutor and two assistants, the lead tutor was nurse trained and the two assistants were both practice nurses who specialised in diabetes care. There were eight people on the course, five had consented to be interviewed and for the observation part of the study and the remaining three had consented only to the observation part of the study. The group was a mixture of people who had diabetes for years and some who had been diagnosed more recently. Six people had type 2 diabetes, one person had type 1 diabetes and one person accompanied his wife (participant 2XP).

#### *Distributed Health Literacy*

The way the class was set up and operated facilitated the distribution of health literacy skills and practices between the participants. For example, all eight participants sat around a table with the tutor and the two nurses amongst them. Prior to the start of the class and in the breaks participants chatted with each other and engaged in conversations about issues related to their own health literacy practices. They shared their knowledge and skills of diabetes and talked about their experiences of managing diabetes. For example, they talked about the importance of eye care, how to manage blood glucose levels and self-monitoring techniques. They also had conversations about information sources, accessing health services and experiences of communication with health professionals. Participants who shared their understandings and skills became *health literacy mediators*.

Some group members who had had diabetes for some time acted as *expert advisors* by sharing information with those who were more newly diagnosed. The types of health literacy skills that were distributed through health literacy mediators within the X-PERT Diabetes class were associated with food literacy (e.g. through sharing information about foods and recipes), interpersonal health literacy (e.g. through experiences of consultations with GPs, nurses and diabetes specialists) some

interactive media health literacy skills (e.g. through providing details of information sources), and some critical health literacy (e.g. through recruitment for local Diabetes UK branch members and participation in fundraising events).

Below is an extract from the observation notes, participant 2XP shared her low sugar cake that she had made.

*X-PERT diabetes programme – week 4*

During the break one person (participant 2XP) gives out portions of a cake that she has made from a diabetes recipe book. Everyone takes a piece of the cake and the group then talk about cooking and discuss cooking tips that use less fat and less sugar.

Below are a few comments that participants made about learning information and self-management skills from others.

The more I'm getting into it with the X-PERT programme the more I'm realising I'm talking to people that I know are diabetics and well informed diabetics. (Participant 3XP)

But if you are prepared to go and spend an hour or so in these different groups, well then you can get.... I mean you can get a lot off the bloke sat next to you. You know if you were sort of struggling for which is best and what isn't best well you've only got to listen and they say I usually do this or I usually do that and that's what it's all about at the end of the day isn't it? (Participant 1XP)

*Social Cohesion and Social Capital*

The X-PERT group were more cohesive than the groups of participants in the Cardiac Rehabilitation Programme and the Expert Patient Programme. This may have been partly because of the way the class was designed and delivered and also partly because of the local culture. The location of the classes was in a valleys community in South Wales where there is usually a strong sense of community and people tend to have interconnections. At least half the group knew each other, either from the local area or their involvement with the local branch of Diabetes UK, and some shared the same healthcare providers. Participants in this group were more of a homogenous group and they had more in common. Thus, they shared a disease identity that helped bond them as a group.

Social capital refers to the features of social organization such as networks, norms and social trust that facilitate coordination and collaboration for mutual benefit (Coleman 1988). The social capital that is available within a community known to have a positive effect on individual health status (Kawachi and Kennedy 1997). There seemed to be more social capital available within this group than the others. This was evident in the ways that participants exchanged advice on how they managed their diabetes, shared food and recipes, brought in books to share with others and one even passed on glucose monitoring devices with instructions how to use them. For example, participant 1XP had given advice to participant 4XP about monitoring blood glucose and brought in a spare unused monitor for her to have. Participant 2XP brought homemade low sugar cakes and offered cooking and recipe advice to others. Participant 2XP had also recruited the more recently diagnosed participants and some others in the group to join the local branch of Diabetes UK. She invited them to a fundraising event at her home and to local meetings where they could meet other people with diabetes and get expert advice from guest speakers.

Below is an extract from the observation notes where participant 2XP attempts to recruit participants to a local Diabetes UK meeting group:

*X-PERT diabetes programme- week 1*

Three people in the group are members of Diabetes UK local branch and attend regular meetings. Participant 2XP and her husband talked to the others in the group about the meetings, telling them about experts that come and speak to them and fundraising events that she organises. She encourages others to come along and gives out contact details.

*7.1.2 Distributed health literacy, social support and retrospective understandings in the cardiac rehabilitation programme*

*The Programme Setting*

The education component of the rehabilitation programme took place on Wednesday lunchtimes in a lecture room at a leisure centre. There were two to three cardiac rehabilitation nurses and a physiotherapist who set up the room and introduced the

speakers. Some of the talks were also delivered by the cardiac rehabilitation nurses. Each class had approximately 18 patients in attendance each week. There were five study participants attending the course and all others were aware of the student's presence but were not part of the study. All attendees sat in rows of chairs facing the front of the lecture room. After the lecture some moved on to the exercise class in the dance studio within the building for the physical part of the Cardiac Rehabilitation Programme.

#### *Distributed health literacy*

The cardiac rehabilitation programme facilitated the distribution of mostly knowledge-based health literacy (i.e. understandings of food and health, health risks and biological processes) between the participants. At the beginning of the education class people tended to gather in their seats and begin to have conversations in small groups. They talked about their experiences of surgery and how they were recovering; they also talked about medications and experiences of side effects. Sometimes some of the men talked about returning to leisure activities (e.g. playing golf) and getting their fitness back in order to return to work. Half way through the class there was a coffee break where people chatted again. During the exercise classes participants carried out gentle exercises as a group and in pairs and engaged in further conversations with each other.

The programme was run on a rolling entry basis and new patients joined every week. Hence, some were further along with their rehabilitation than others and seemed to sometimes offer support and encouragement to others in addition to advice and information. The distribution of health literacy within this group of participants operated as a source of social support and helped participants cope with what they had been through. For example, participants seemed to enjoy listening to other people's experiences of surgery and how they were coping afterwards. They shared their understanding of what had happened to them and were comforted by being around other people who had gone through some of the same things that they had experienced.

By learning about others' experiences and sharing knowledge and understandings, health literacy was developed in a way that helped participants make sense of processes that they had been through and reflect on *past information*. Below are some comments about sharing experiences that participants commented on when asked about their experiences of being in a group and learning from others:

I enjoy the classes; I think they've been really good. You sort of almost feel, well let's go every other day which most probably wouldn't be a good thing in the long run. I enjoy that and, interacting and talking to other people who have had the same thing, that's got a lot to do with it. (Participant 3CR)

I enjoyed it very much, I found that being with other people was very interesting because we all talk about what we had done and all of that and so more or less compared notes. (Participant 1CR)

The fact that you know... you are talking to people that have had the same experiences as you, I thought was quite nice. (Participant 5CR)

### *7.1.3 Limited opportunities for distributed health literacy in the Expert Patient programme*

#### *The Programme Setting*

The classes took place on Friday afternoons in a classroom at a modern church centre. Each class was two and a half hours long with a short coffee break in the middle. The class was lead by the programme leader who was based at the Local Health Board and a lay tutor who was a volunteer. The programme leader was not a trained healthcare professional but the lay tutor worked as a nurse before she became too unwell to work. The programme leader and the lay tutor sat at the front of the room and used a flip chart and wall charts to teach the class. There were 13 attendees in the original group (including five interview participants), they had a range of conditions, some had physical and painful conditions such arthritis and others had mental health conditions such as bipolar disorder or depression and anxiety disorder.

Five participants from the group agreed to be interviewed and the remainder agreed to the attendance of a participant observer. One programme participant left during the coffee break and never returned, and a further four dropped out after week one (including one interview participant) and another two dropped out after week two (including one interview participant). One participant said that the course was not

what she expected and she felt that she had managed her condition well and that she was hoping for more opportunities to meet other people and have discussions with them. Another participant who left after week one said that he had travel plans coming up that interfered with him attending regularly and thought it was best to give up. Another interview participant finished the course after week three because she had surgery on her knee. However, she did agree to a second interview and planned to attend another course when she recovered. Thus, there were three remaining interview participants within the group (1EP, 2EP and 3EP). Two further participants (4EP and 5EP) had completed another course in a different location that was not included in the observation part of the study.

#### *Limitations on distributed Health Literacy*

There were fewer opportunities for participants to discuss their health literacy practices on an informal level within the Expert Patient Programme compared to the X-PERT Diabetes Programme and the Cardiac Rehabilitation Programme. There were limited opportunities for participants to discuss their own personal experiences within the class. This was because there was a lot of material for their lay tutor to get through in the two and a half hour time frame. Furthermore, there were fewer opportunities for participants to help build understandings of their own because there was greater heterogeneity within the group, no two participants had the same condition and they were less likely to have shared similar experiences.

Below is an extract from the observation notes of week 1 illustrating the short amount of time that participants had to talk about their own experiences in the class-time.

#### *Expert patient programme- week 1*

The first task was to identify problems associated with living with a long-term condition. The tutor went around the class and asked each person. She clearly told them that she was not interested in what condition they had. They were given very limited time to talk. The tutor rushed around everyone, cutting them off abruptly if they spoke for too long.



Participants did have short conversations about their day to day life, their health status and experiences with health care services during the refreshment break. It seemed that there was more social support occurring between participants than learning from each other in the group that was observed. Most participants were unable to work because of their condition and many of them experienced some degree of social isolation. Positive comments from participants about the course seemed to relate to being around others and being part of a group. At the end of the course participants were encouraged by the course tutor to swap contact details to stay in touch as a group.

## ***7.2 Part Two - the development of health literacy through formal learning***

The patient education and self-management education delivered through the programmes in this thesis had the potential to develop health literacy by developing participants' knowledge and understanding of their condition and by teaching participants' health literacy practices and skills that are associated with various health literacy categories identified within this thesis. This section will describe the health literacy practices that were taught and how health literacy was developed through the educational components of the programmes. Firstly, the contents and delivery of the programme will be discussed and secondly, there will be discussion around the categories of health literacy that were potentially developed through each programme.

### ***7.2.1 The X-PERT diabetes programme***

#### ***The Delivery of the Class***

The class was delivered by a tutor (nurse trained) and two diabetes nurses. Some of the topics covered were an explanation of what diabetes is, medications, self-monitoring, healthy eating, carbohydrate awareness, understanding food labels, preventing complications and available resources. The tutor used a whiteboard to illustrate biological processes and the effects that diabetes can have on the body. Participants were given a handbook to support the classroom learning, all the topics covered in the class were included in the book and there were exercises and quizzes to test learning. The book included a lot of information about foods, medications and self-management techniques for diabetes.

*Scientific literacy - understanding the meaning of biological test results*

The programme helped participants develop scientific literacy by increasing their understandings of their body and how their weight and measurements may affect their health. Participants had the opportunity to develop their health literacy practices through learning how to interpret relevant test results and how to self-monitor their blood glucose and manage prescribed medications in order to maintain a good level of control over their diabetes and prevent further complications. Participants were asked to complete a health profile which included their height, weight, body mass index, and tests of their blood glucose level, HbA1c, blood pressure, total cholesterol, good cholesterol, bad cholesterol, triglycerides and their albumin: creatine ratio. They were informed of what these tests and measurements mean and what the normal ranges were. Participants were also asked to bring a list of their medications and informed of the effects of prescribed medications on achieving optimal results. Below is an extract from an interview where participant 2XP talked about learning how to manage her blood glucose levels:

..this last week at the course we were on I found that very good, it's actually educated me this last week....because even though I thought I was doing it pretty good all these years I wasn't. So you know even though I expected to know everything on this course I didn't and I am glad that I am learning something from it. (Participant 2XP)

*Biological processes*

Participants developed their understanding of the biological processes involved in diabetes every week in the classes. In the first class the course tutor displayed a diagram of the body and informed the group members about the process of carbohydrate digestion, the production of insulin and how diabetes is related to not enough insulin being produced (insulin insufficiency) or the inability to use insulin effectively (insulin resistance). In each subsequent class this information was recapped and participants were asked to help insert missing information from the diagram. For example, they were asked to explain what happens when body cells become overweight and explain the difference between the processes involved in insulin resistance and insulin insufficiency. Participants were also informed about how medications work in their body, the effects of some physical symptoms

associated with diabetes, and how hyperglycaemia and hypoglycaemia affect the body.

#### *Evidence of learning*

Most participants seemed to have developed their scientific literacy by forming an understanding of the biological processes in the development and treatment of diabetes by the end of the six-week programme. There was some indication of their level of understanding in a quiz at the end of the course where participants were able to identify pictorial representations of body cells, the pancreas, blood glucose and insulin and explain the biological processes that they had learned throughout the programme.

#### *Risk literacy*

##### *Preventing long-term medical complications*

Understanding the risks of long-term medical complications associated with diabetes and understanding how to prevent their onset is part of what is described in this thesis as risk literacy. Throughout the X-PERT programme participants were taught about the risk of potential long-term complications associated with diabetes (e.g. foot ulcers, heart disease and retinopathy). They were informed of risk factors for developing such complications and how they could care for themselves and use healthcare services to prevent their risk. Some participants already understood the risks and had self care practices in place and used foot care and eye screening services. Some who were more recently diagnosed did not have a good knowledge and understanding of their risk of complications and had not been offered access to eye screening and foot care services. By becoming more risk literate through the X-PERT programme one participant (3XP) felt she was more in control of her diabetes. She was given the information in a way that helped her understand why foot care was important and this knowledge and understanding made her feel in control.

They took us through the condition in a logical way and you could connect everything, you know so it wasn't "oh you must take care of your feet" but you don't know why or you find that you don't heal so quickly but you don't know why. They took us through it all very logically so that it all connected up and you came away feeling that you were in control and yes that was the point, that's what I benefited from. I felt in control. (Participant 3XP)

### *Food literacy*

#### *Understanding the importance of diet*

Understanding the importance of diet in managing diabetes and the ability to interpret food labels and make appropriate food choices is part of what is described in this thesis as food literacy. The X-PERT programme was heavily focused on food and nutrition for managing diabetes and thus focused on the development of food literacy. Participants were taught about the benefits of limiting their carbohydrate intake and which types of fats to limit and avoid. They were shown how to examine food labels and to be aware of carbohydrate and fat content in food. There were several practical exercises where participants had to examine nutritional contents on food packages and work out what their usual daily carbohydrate intake was.

Participants were also informed about healthy portion sizes and the importance of eating at regular intervals. Participants had the opportunity to develop their food literacy and learn new health literacy practices by understanding nutritional contents in their usual food choices, and understanding the relationship between managing their diet and controlling their medication and blood glucose levels. Participants in the X-PERT group were more motivated to make changes in their diet than participants in the cardiac rehabilitation group. Below are some interview extracts where participants talked about food changes that they had made based on what they had learned in the programme:

I knew quite a bit before but I was still able to learn a bit more especially on the diet side of things and since then I've been counting carbohydrates and monitoring my food a lot more, trying desperately to improve my glucose readings. (Participant 2XP)

I listen to what they told me on the course and yes I am carrying most of the practices out because like I told you, when I was on the course God I'd pick this up in the supermarket and put it in the trolley and not think I don't do that anymore. You know, for (husband) I know certain things that he'll like and I say to him well you can have it this week but only once now and again, and he said "yes ok whatever, what are you having", ah I'll have something but I never have what he has because the saturated fat is so high in there and the sugars and I think no, and I wouldn't have thought like that before I went on the course. (Participant 4XP)

### *7.2.2 Cardiac rehabilitation*

#### *The delivery of the class*

The classes were hosted by the cardiac rehabilitation nurses and physiotherapists based at the local hospital. Each week a guest speaker delivered a lecture that was projected onto a screen using a laptop computer. The first class that was observed for this study was delivered by a cardiac rehabilitation physiotherapist and covered physical activity; the second class was about healthy eating and was delivered by a cardiology nutritionist, the third class was about stress management and was delivered by occupational therapists; the fourth was about medications and was delivered by a hospital pharmacist; the fifth was about risk and delivered by the cardiac rehabilitation nurses; and the sixth was about sexual relations and was also delivered by the cardiac rehabilitation nurses.

#### *Biological processes and scientific literacy*

There was potential to develop scientific literacy throughout the cardiac rehabilitation programme. Developing scientific literacy served three main purposes: (1) to help participants understand some of the biological processes that lead to heart disease and how they affect heart functioning, (2) to understand some of the medical procedures that they had gone through, and (3) to understand how medications work and the effects that they can cause. Participants were shown diagrams and animated representations of the heart showing how high blood pressure affects the heart, how arteries become blocked and representations of procedures that some of them had had done (such as having a stent inserted and by-pass surgery).

Although participants were given some of this information prior to their surgery, some seemed to have problems processing the information and forming an adequate understanding due to raised anxiety. Developing participants' biological knowledge and scientific health literacy in the cardiac rehabilitation programme enabled them to clarify misunderstandings and gaps in their knowledge and gain a better understanding of their heart condition. Some participants felt that a better understanding helped them overcome some of their anxieties and fears about their experience of having heart surgery and aid in their rehabilitation.

Below is an extract from the observations where a woman who participated in the course but was not interviewed talked about her knowledge of heart disease before her surgery.

*Cardiac rehabilitation- week 2*

One woman on the course told me that she didn't know anything about heart disease before she had her operation. She talked about watching someone have the same operation on television. She said she only watched half of it but wished that she had watched it all. She wanted to see what had been done to her.

Below some participants talked about what they had learned on the course.

I think that a couple of talks that we've had down at the sports centre talking about food and talking about stress they were very helpful. I think you learn gradually to have a bit of confidence in yourself and um I suppose you are starting to understand exactly what has happened and why. (Participant 3CR)

I think it was important because it did make me aware of some things I wasn't sure of before or hadn't given any thought to before. I can't think of an instance but I know there were things like the types of drugs that were being prescribed and things like that. What they do and what the side effects of those can be as well. (Participant 5CR)

*Risk literacy*

Each class covered an element of risk literacy by identifying potential risks to heart functioning and helping participants understand how to prevent and manage them. The class given by the physiotherapists advised participants how to exercise safely and how to return to usual daily activities. The class given by the nutritionist advised participants how to eat healthily in order to manage weight, cholesterol and blood pressure levels. The class given by an occupational therapist on stress covered the risks that stress posed on the heart and advised on methods of reducing stress. The pharmacist gave advice on the risks of side effects with certain medications and advised on the suitability of alternative medications to replace them and there was one class given on risk that specifically covered all the risk factors for heart disease.

*Food literacy*

*Dietary advice and risk management*

The dietary advice given in the class provided the opportunity to improve participants' food literacy and influence some of them to make necessary changes in their diet. The cardiology dietician talked about healthy food choices and portion sizes, types of fats, food labelling and the positive benefits of eating healthily for the heart. There were some psychological elements given in the talk that were centred around behaviour change and relapsing. However, although participants listened to the advice and learned information that contributed to their food literacy, not all participants were motivated to change their usual diet as a result of the class.

The dietician talked about the Body Mass Index (BMI) and healthy weight ranges. However, none of the participants appeared to be overweight and all interview participants claimed to have eaten a healthy diet before their surgery, except for participant 3CR who was underweight but still felt she did not always make healthy choices.

Participant 1CR did not plan to make any changes in her diet after attending the education class. Below are her comments where she talked about listening and taking note of the dietary advice given in the class but made a decision not to follow the advice and stick to her usual 'sensible' way of eating.

I've taken note of it; I must admit that I don't follow it. I won't follow it strictly but it is very... I thought that last Thursday in particular it was very interesting and I mean I don't go over the top you know when eating anything. I just sort of eat fruit and veg as they say but I'm not as strict. I don't follow it strictly. Like I think, listening to some people talking after Thursday, they were going to follow it really by the letter. But I must admit I don't think I am, I just go carefully. (Participant 1CR)

In contrast, participant 3CR was more influenced by the advice given in the class and came to realise that she had not been eating a good diet prior to her condition and made some changes.

Well when we went to rehab they were talking a lot there about diets and different things. So I have changed my diet from the point of view that I don't eat as many cakes or biscuits or crisps like that. I do watch what I eat, I eat quite a lot of vegetables now and fruit and fruit juice. But I still have my glass of wine every day. (Participant 3CR)

### ***7.2.3 The Expert Patient programme***

#### *The delivery of the programme*

The delivery of the classes was focussed on the tutors talking to the participants in a scripted manner. The tutor seemed to be reading from a course manual that was used to teach all participants on the programme in the UK. There were also some group exercises where participants practised distraction and relaxation techniques.

Participants were taught about managing common symptoms, managing difficult emotions, physical exercise and healthy eating, and communicating effectively.

Participants worked in pairs or as a whole group to identify problems and provide answers and potential solutions to questions about managing and coping with a long-term condition and communicating with health professionals.

‘Action planning’ was a main feature of the programme and each class ended with participants making an action plan where they pledged to carry out an activity for the upcoming week. Action plans involved activities such as going for a walk or swimming for specific amount of time, at specific times and on specific days of the week. All participants had to complete an action plan that was deemed achievable and report back their progress at the beginning of the following week’s class.

If a participant was unable to achieve their action plan then it was discussed with the group and other participants were asked to suggest ways that that person could achieve their planned actions in the next week.

#### *Food Literacy*

General advice about healthy eating was given, which was mostly advice about food choices, portion sizes and weight management. The advice given was not as in-depth as that given in the X-PERT programme and in the cardiac rehabilitation programme and so the potential for developing food literacy was more limited to general knowledge and skills in making basic food choices rather than skills in examining nutritional information.

#### *Scientific Literacy*

The only potential for developing scientific health literacy was centred on symptom recognition and management in relation to common symptoms experienced in long-term conditions. There was no in-depth biological information given on any specific condition.



### *Interpersonal Health Literacy*

The category of health literacy that seemed to have the most potential to develop on the programme was interpersonal health literacy. Participants were taught interpersonal health literacy practices and skills that could be used in personal and social relationships with friends and family. These interpersonal health literacy practices involved expressing their feelings, minimising conflict, asking for and accepting help, refusing requests and listening to others. They were also taught interpersonal health literacy skills and practices that could help them actively communicate their concerns more effectively with health professionals. These involved health literacy practices such as asking for more information, planning appointments and preparing an agenda for discussing within a consultation, asking questions and clarifying instructions.

There were role play and free think exercises where participants had the opportunity to input their ideas and thoughts to practise communication strategies. During interviews some of the participants commented on the interpersonal skills they had learned on the programme and had decided to use them in consultations and in their personal relationships.

I did learn things, I mean the section on communication that they did as part of the expert patient programme I thought was particularly helpful and really made me think about the 'I' messages, the 'you' messages which can be quite aggressive or controversial. So I've particularly thought that was useful and I now try to use it because if you wanted to persuade somebody to do something or somebody to help you, you can communicate with them effectively, it's much the best option isn't it?  
(Participant 4EP)

### *Critical and Civic Literacy*

Both critical health literacy and civic health literacy involve understanding what it is to be a patient in the society in which one lives, what rights one is entitled to as a patient and how individual and social action can be taken to exercise them. These were covered in the Expert Patient Programme; participants were educated on their role as a patient within the UK National Health Service, the type of care they were entitled to, their rights as a patient (e.g. access to medical notes, access to a second opinion), and legal issues (e.g. assigning power of attorney and writing a living will).

One participant from the group (5EP) gained an understanding of her rights from the programme and had taken action based on some of the topics covered in the programme. She had requested access to her medical notes to help her understand what is happening about her treatment and to prepare her for communicating with her consultant.

I think it does make a difference because I'm actually... I'm having access to my medical notes now which before that I was like.... Where the course just reinforces that you are the patient who cares about you and you should have some say in it. When I see my consultant in October I can go in with a list of questions and for the answers which I haven't really gotten before. (Participant 5EP)

### ***7.3 Part three - informal learning opportunities***

Some participants had the opportunity to engage in informal discussions with the programme tutors. These discussions were sometimes about symptoms, medications, and using healthcare services. Each programme had a different approach to teaching and there were differing levels of access to individual information in the three programmes. In the cardiac rehabilitation and the X-PERT diabetes programmes there was access to support and disease specific information from specialist nurses. Some of the information and advice reconfirmed participants' understandings of their condition, helped them manage it and directed them to further information and services. In the Expert Patient Programme there was less access to informal learning and the programme was lay led, so there was no specialist advice or information given. The tutors on the programme are trained to deliver the programme from a script and did not appear to be encouraged to answer individual concerns. This section will describe how and whether health literacy skills and practices were supported through informal discussions with the programme tutors.

#### ***7.3.1 The X-PERT diabetes programme***

##### ***Nurse support in facilitating health literacy development***

The course tutor and two nurses facilitated the development of health literacy skills and practices on a one-to-one basis with all the group members. They were supportive and answered individual questions from the group members during break times and at the start and end of the class. It seemed easy for them to engage with participants because they sat around the table amongst the group. They seemed to invite participants to engage in one-to-one conversations about their experience of managing

their own diabetes and got involved with conversations that occurred between participants. They offered advice on participants' individual concerns and sometimes suggested that some seek checks from health services and sometimes advised them on issues to discuss with their GP. Below is an interview extract where participant 1XP talks about the course tutor and the nurses answering individual questions from the programme participants:

I said anything you wanted to know was all there for you I said and there was three there all the time, on the odd occasion there was four there. So I said they were all firing questions in different places, so I said as far as I was concerned it was an excellent course. (Participant 1XP)

Participant 4XP was pleased with the support and encouragement that the course tutors gave her in completing the programme and helping her come to terms with diabetes.

So everything from the day I walked in there. I mean they knew that I was really worried about what I had and I know it was only a small gesture or may be "you will come back next week then" and I came out of there and I said to them "yes I will come back" and perhaps I wasn't very convincing but I came out from there and I thought they are concerned that I go back then you know and I wouldn't have let them down under any circumstances then you know because I wanted to go back. (Participant 4XP)

### *7.3.2 Cardiac rehabilitation*

#### *Nurses and Physiotherapist Support with Rehabilitation*

The cardiac nurses and the physiotherapists answered questions and gave individual advice and information to participants during break times and during conversations that took place within the exercise component of the class. The nurses stood amongst the participants at break time and both the nurses and physiotherapists interacted with participants on a one to one basis a number of times during the exercise class to check how they were feeling and monitor their heart rate. Participants also had the opportunity to talk to the pharmacist, dietician and occupational therapist on the weeks that they delivered the class. Informal conversations with all the health professionals that they had access to on the programme supported their development of health literacy by reinforcing the understanding that they had achieved throughout the programme. The individual information, advice and support given to participants

by the nurses and physiotherapists helped some of them come to terms with their surgery, manage side effects and symptoms, recover from their surgery and also rebuild some of their confidence that they had lost regarding getting back to usual activities and moving on with their lives.

They take you at that vital stage when everyone else has left you alone because you've got that 3-6 month period where there isn't anything you can do you just have to kind of sit still and wait for everything to heal and do some gentle exercise and they take you at that point and they hold your hand and say this is what you are going to do. It is such a vital part that everyone I've spoken to loves it and it gives you so much more confidence to go out and actually do stuff. (Participant 5CR)

But they were really interested in you like you know it wasn't a terrible chore like they were actually interested in and ... oh it's their job and you can see people making progress and getting better and it must be satisfying isn't it. (Participant 2CR)

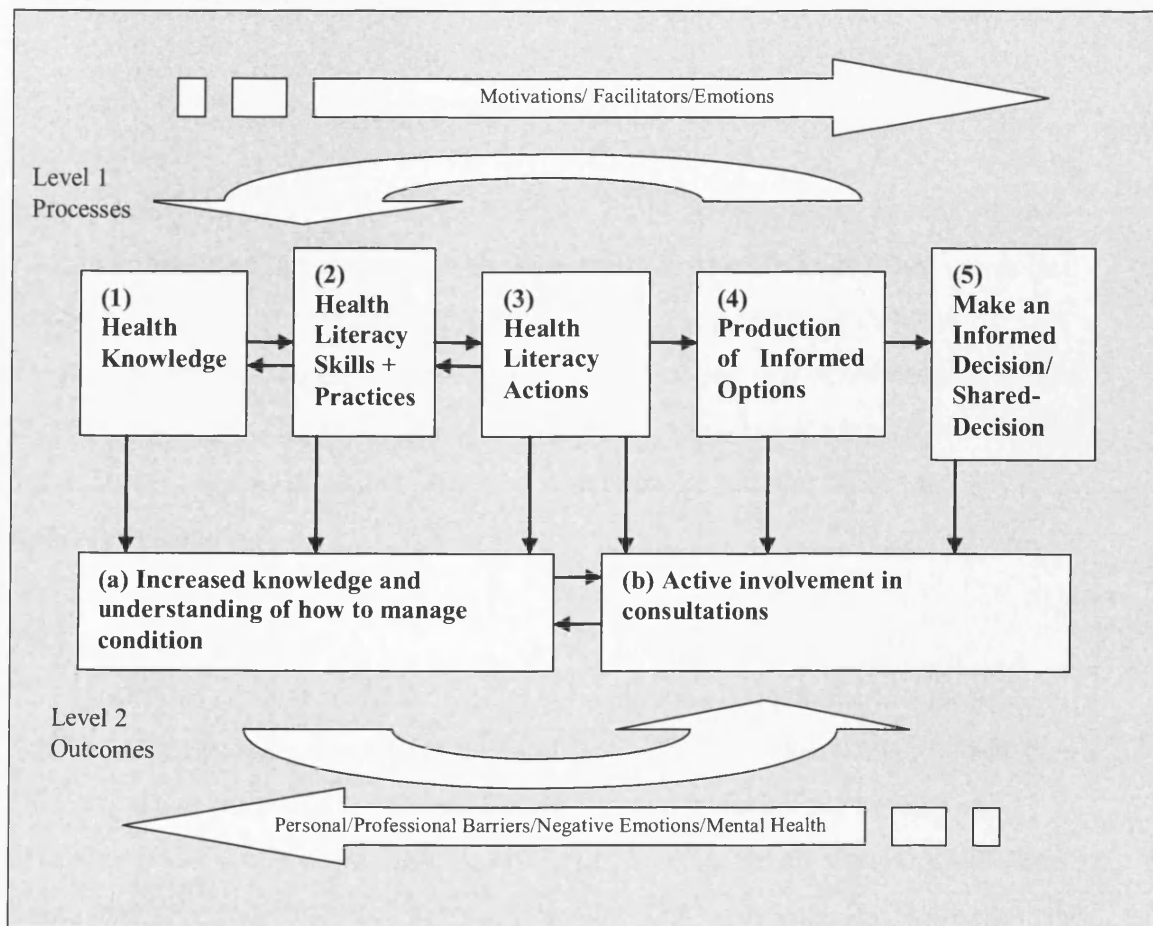
### *7.3.3 The Expert Patient programme*

There were no observed cases of health literacy developing through informal learning in the Expert Patient Programme. This may have been because there was not much time for participants to have informal conversations with the tutors except during the break time. There was a table with leaflets on it and sometimes the tutors would distribute some of the leaflets and direct participants to further information sources. Because the course was a generic self-management course and the tutors were not trained nurses there was no information about specific long term conditions discussed at an informal level. There was an element of distance that separated the participant from the tutors and may have also prevented informal learning opportunities. For example, the tutors sometimes positioned themselves on chairs at the front of the class during the break and may have appeared not so accessible to participants who may have wanted to discuss specific concerns. There were no comments about the delivery of the class or any informal learning made by participants during the interviews.

#### 7.4 Part four - the development of health literacy categories in patient education programmes and intervention points in the Pathway Model

This section will explain how patient education acted as a health literacy intervention and show how participants progressed through stages of the Health Literacy Pathway Model (see below for a copy of the model featured in Chapter 6) through (1) distributed health literacy (2) taught elements of the patient education programmes, and (3) informal learning opportunities between participants and tutors and health professionals who delivered the programmes. These methods of learning will be mapped onto the model (see figure 7.1) at various intervention points.

Copy of figure 6.1 The Health Literacy Pathway Model



*(1) Distributed Health Literacy*

Although there were various opportunities for distributed health literacy across the different groups, the health literacy skills and practices that were shared amongst participants from all the groups helped participants move along the Pathway Model. Sharing experiences and specific advice on coping with symptoms helped some participants understand their condition and how to manage it better.

This helped participants move from **stage one** to **stage two** and achieve **a) increased knowledge and understanding of how to manage condition**. Sharing experiences of using health services, communications with health professionals and treatment options helped participants move from **stage one** through to **stages two, three, four and five** in some cases and influenced some participants to become more active and thus progress to **b) active involvement in consultations**.

*(2) Taught Elements of the Programmes*

The taught elements of the programmes helped participants develop a range of health literacy skills and practices. Both the X-PERT Diabetes programme and the cardiac rehabilitation programme facilitated the development of knowledge based categories of health literacy such as: scientific literacy, risk literacy, and food literacy.

These categories are closely associated with stage one and two of the Pathway Model (health knowledge and health literacy skills). Both programmes were focussed on the development of knowledge and skills and map onto the pathway model at **intervention point 1**.

*7.4.1 Cardiac rehabilitation*

The educational component of the cardiac rehabilitation programme was more focussed on developing knowledge and built on participants' knowledge of their heart functioning and surgical procedures. The cardiac rehabilitation programme also developed participants' understandings of healthy eating, physical activity and stress management in relation to their heart functioning. The knowledge and skills learned through cardiac rehabilitation gave participants confidence to return to activities, influenced some behaviour changes and helped participants come to terms with the fear and anxieties they had relating to recovering from major surgery. There was some movement from **stage one (health knowledge)** to **stage two (health literacy actions)** in the Pathway Model but the overall outcomes of in health literacy development were

linked to **stage a on level two (increased knowledge and understanding of how to manage condition)**.

#### *7.4.2 The X-PERT diabetes programme*

The X-Pert programme facilitated both knowledge and skill based learning and seemed to focus on self-care practices. The programme developed participants understanding of diabetes and taught them skills that they could put into practice to manage their diabetes more effectively. There appeared to be more movement from **stage one to stage two** through the X-PERT programme than there was with the cardiac rehabilitation programme, mainly because there are more self-management tasks taught in diabetes education. The main outcomes of developments in health literacy were related to **stage a (increased knowledge and understanding of how to manage condition)**. However, some participants were motivated to use some of the information that they had learned to access health services and introduce topics of discussion with a health professional. Thus, they were moving from stage a to **stage b (active involvement in consultations)**.

In both the delivery of the X-PERT and the cardiac rehabilitation programme there was no emphasis on developing ways of using knowledge in consultations, developing communication strategies or involvement in treatment decision making and activating patients in consultations. The X-PERT programme was more about self management skills and controlling diabetes and the cardiac rehabilitation programme was more about making changes to life style, diet, physical activities and awareness of risks in order to return to an optimal quality of life.

#### *7.4.3 The Expert Patient programme*

The ethos of the Expert Patient Programme was aimed at empowering patients and helping them improve their quality of life, take control over their health and treatment, and effectively use health services. There were generic skills and practices taught on the programme that helped participants understand and manage common symptoms of long-term conditions and practices that helped them develop strategies to improve their quality of life. The communication skills taught in the Expert Patient Programme developed participants' interpersonal health literacy skills (i.e. communication and negotiation strategies) that they could then use as health literacy

actions (i.e. asking for services and exchanging information). These developments can be mapped onto the Health Literacy Pathway Model at **intervention point 2** and helped participants move from **stage 2 (health literacy skills)** to **stage 3 (health literacy actions)**.

In terms of health literacy outcomes (level two in the model) participants were given skills that could move participants from **a) increased knowledge and understanding of how to manage condition** to **b) active involvement in consultations**. There was no movement from **stage one** to **stage two** in terms of disease specific knowledge and skills, possibly because the course was generic or the content of the course.

Furthermore, some participants who had experienced their condition for some time already had good knowledge of their own condition whilst others were learning through communications with health professionals and searching the internet.

### *(3) Informal Learning opportunities*

Some disease specific information and advice was given to participants in the X-PERT and cardiac rehabilitation programmes through informal conversations with the tutors and health professionals who delivered the programmes. This information was sometimes about the condition, surgical treatment, managing symptoms, treatment choices, accessing services, and sometimes about diet, exercise and lifestyle. These informal learning opportunities helped participants move from **stage one** through to **stages two and three** and influenced **stages three and four** with some participants. Thus, informal learning helped achieve **a) increased knowledge and understanding of how to manage their condition** and on some occasions **b) active involvement in consultations**.

In the Expert Patient Programme there were no observed opportunities for informal learning and no access to advice from health professionals. There was no mention of any informal advice given in interviews with participants. However, if there was any self-management advice or advice about access services given through informal conversations, it would mean that participants would be more likely to move from **stage two** to **stage three** and achieve **a) increased knowledge and understanding of how to manage their condition**.



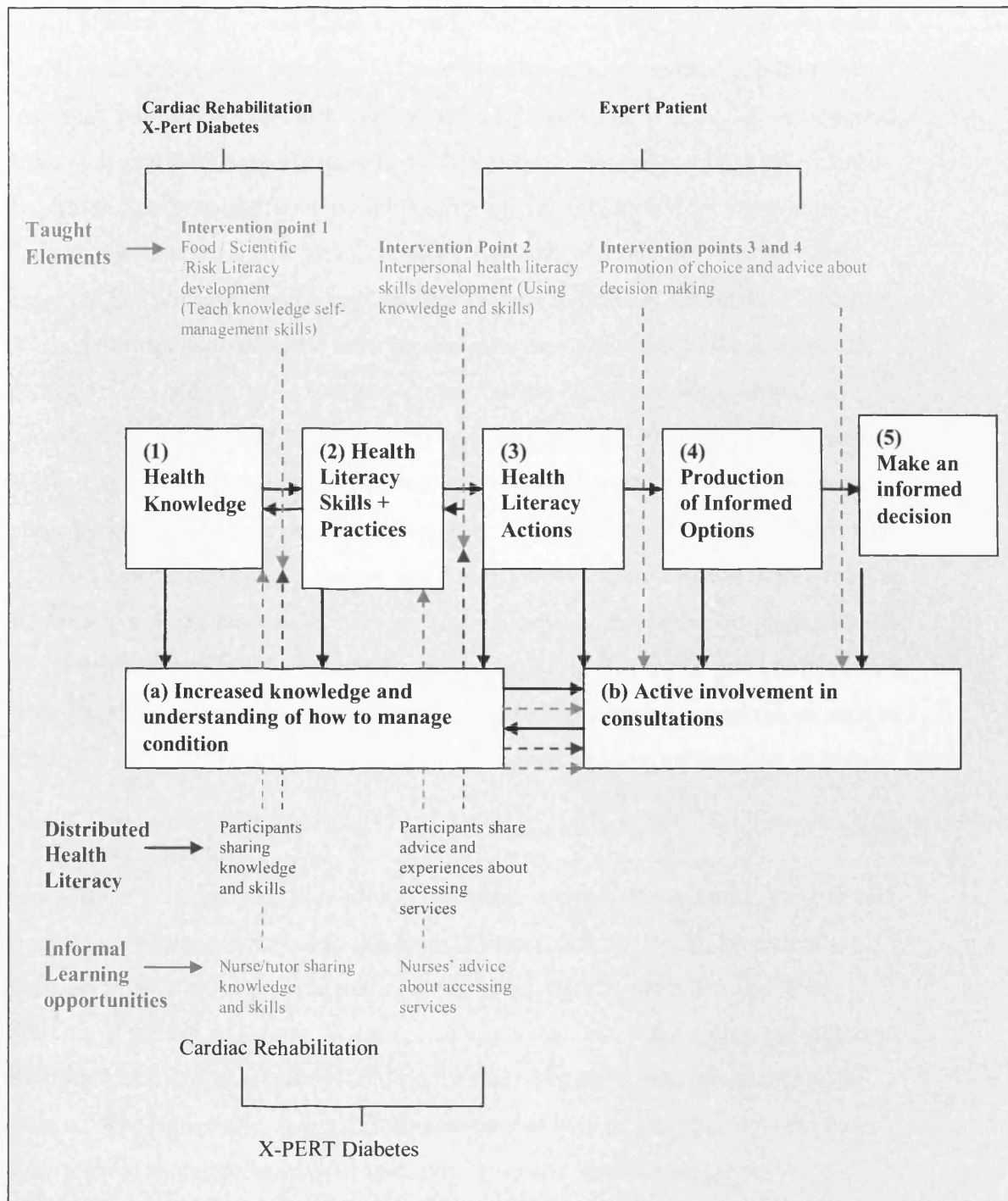
#### 7.4.4 Addressing personal barriers to health literacy development

By participating in a patient education programme, some participants were able to address some of the personal barriers to the development of health literacy and progression through the stages in the Health Literacy Pathway Model (see chapter 6 for further explanation of these barriers). The taught elements helped some bridge gaps in their understandings and clarified misunderstandings. Some participants (e.g. participant 3CR and 5CR) in the cardiac rehabilitation group felt that a better understanding about what they had been through in relation to their surgery helped them cope better and overcome their fears and anxieties. The social and emotional support gained through informal learning and talking to other participants helped participants reduce their fears and anxieties and come to terms with their condition.

There were reports of improved confidence in most participants in the cardiac rehabilitation group and the nurses in the X-PERT programme helped one participant (participant 4XP) come to terms with her diabetes and understand what it meant for her. Accepting diabetes helped her engage more with information and make dietary and lifestyle choices.

The model on the next page (figure 7.1) shows how the taught elements of the programmes, informal learning opportunities and distributed health literacy between participants map onto the health literacy Pathway Model. An important feature of the model is that it shows health literacy as a *process* that evolves in patient education settings and is also an *outcome* of formal learning through patient education and informal learning opportunities that are presented within the same setting.

**Figure 7.1 the Pathway model showing the intervention points addressed by patient education programmes**



#### **7.4.5 The Comparison Group**

Participants in the comparison group had not demonstrated any developments in their health literacy over the time of the research. The reasons for a lack of development in health literacy may have been due to there being no changes in their condition and treatment and that they had not utilised health care services over the 12-week period since their first interview. Participant 1C had not experienced any health problems and had not had a consultation with his GP since his first interview. Participant 2C had one consultation with a psychiatrist and had seen a community mental health nurse but had not experienced any changes in her condition or treatment. Participant 3C did not respond to requests for a second interview so was not followed up, and participant 4C had not had experienced any changes in her condition or had any consultations with her GP. Some participants in the patient education groups were newly diagnosed and had more to learn over the period of the research. However, participants in the comparison group had been living with their condition for longer than participants in the other groups and had developed knowledge of their condition and how to manage before the research began. They had learned about their condition and developed their health literacy through interacting with health care professionals, talking with friends and family and more self-directed learning opportunities such as reading health information in books and leaflets, and seeking information online.

#### **7.5 Chapter summary**

This chapter demonstrated how patient education and self-management programmes featured in this study acted as health literacy interventions. Health literacy is characterised as both a process that evolves within patient education and is an outcome of patient education. Social interactions that take place within the delivery of the programme and short periods before the class begins, coffee breaks and as the class is finishing are all sources of information that help participants develop their knowledge and understandings of their condition and how to manage it.

The formal education given in disease specific programmes mostly helped participants develop knowledge based health literacy categories (i.e. food literacy, scientific literacy, risk literacy). The formal education given in the generic self-management programme helped participants develop their critical health literacy and civic health literacy in terms of educating them about their rights and responsibilities

as a patient. The generic programme also helped participants develop communication strategies, thereby developing their interpersonal health literacy and potentially developing interpersonal relationships between participants and their social networks in addition to their relationships with their regular healthcare professionals. Mapping the benefits of these programmes on to the health literacy Pathway Model helps show how the programmes worked at different intervention points along the health literacy pathway towards informed decision making. The programmes helped address some of the personal barriers to the development of health literacy identified in chapter 6 (i.e. problems accepting and adjusting to a condition and emotional barriers to engaging with further information that were associated with fear and anxiety).

To conclude this chapter, most categories of health literacy that were identified in chapter 5 can be developed through patient education programmes and help participants progress through stages identified in the health literacy Pathway Model in chapter 6. Health literacy processes were channelled through the delivery of formal education components, informal learning opportunities made available by those delivering the course, and the distribution of health literacy skills and practises amongst group participants.

## **8.0 Discussion**

### **8.1 Introduction**

The primary focus of this thesis was to explore health literacy from patients' experiences of health and health care and put forward a conceptualisation of health literacy based on how patients with a long-term condition practice and develop health literacy in different health contexts and over time. The second focus was to investigate the development of health literacy through group-based patient education programmes and identify how health literacy may develop through social interactions with health educators and other group members.

The research was carried out through a longitudinal interview and observational study with patients recruited mainly from education programmes. The research was carried out over the duration of their programme and for some months after. Semi structured interviews were used to explore people's experiences around health literacy and to detect developments in health literacy of the course of the research. Participant observation was used to capture the process of health literacy development in patient education programmes.

I will summarise what the research objectives were and in which chapter these were addressed, and then go on to discuss the findings in more depth. The main objectives of the research were:

#### ***To undertake a historical and theoretical review of the literature on health literacy.***

This was done in chapter two in a historical exploration of the evolution of health literacy and the development of health literacy research, evaluation of how health literacy is conceptualised and measured, evaluation of health literacy research on health outcomes, evaluation of models of health literacy and healthcare processes, and health literacy based health education interventions.

#### ***To describe the meaning and experience of health literacy skills for patients with a chronic condition across different health contexts.***

Chapters five and six addressed this objective by describing skills in new and existing categories of health literacy that participants put into practice when self-managing

their condition (at home or in the work-place), communicating with health professionals (in both primary and secondary care settings), social interactions with friends and family (at home, work, or in the community), seeking information and services and participating in decision making (at home, in healthcare settings, and in the community), and in patient education programmes (in the community).

***To describe how patients' understandings and abilities concerning their health and their health literacy practices compare with given definitions of health literacy.***

This was achieved in chapter five where new and existing health literacy categories were explained, based on participants' experiences of health and health care.

***To describe how patients become health literate with their condition and how they experience healthcare communication (including information exchange and informed/shared decision-making).***

This objective was met in chapter six where a health literacy Pathway Model was proposed to explain how and when participants developed knowledge and health literacy skills and how some used those skills to become more active in healthcare consultations and participate in healthcare processes such as seeking treatment options, informed decision making and shared decision making.

***To describe how health literacy may affect patients' experiences of using healthcare services in various contexts and identify possible facilitators and barriers.***

Chapter six also described participants' personal motivations and barriers, and facilitators and barriers created by health professionals that affected health literacy.

***To describe the range of health literacy practices that may be developed through patient education and relate them to definitions of health literacy.***

Chapter seven described how different health education contexts provided health literacy skills across the range of health literacy categories identified in this thesis.

***To describe processes involved in the development of health literacy for patients who participate in self management programmes and how these social interactions differ across groups of patients.***

Chapter seven also explained how health literacy developed in patient education programmes through formal learning and informal learning opportunities (social interactions with tutors, and other group members).

The key findings in this thesis are:

- 1) Health literacy as practised by participants in the current research may be more multi-dimensional than described by health literacy theorists and researchers (Nutbeam 2000; Zarcadoolas et al. 2006; Zarcadoolas et al. 2003). New categories of health literacy such as food literacy, health risk literacy, interpersonal health literacy, interactive media health literacy and distributed health literacy can be used to describe more contextual experiences of health literacy.
- 2) Health literacy was distributed amongst social networks and participants drew on the health literacy skills made available by others as a personal resource. Those who share their health literacy skills and teach others new health literacy practices are described as *health literacy mediators*.
- 3) Health literacy developed along a trajectory that included the development of knowledge, health literacy skills and practices, health literacy actions, abilities in seeking options and realising informed and shared decision making opportunities.
- 4) Barriers to developing health literacy and practising health literacy skills were personal to participants' characteristics and also created by some health professionals who worked in ways that did not support the development of those health literacy skills. In contrast, supportive health professionals worked in ways that facilitated health literacy development, and allowing participants to put their skills into practice.

- 5) Patient education programmes promoted the development of different categories of health literacy (depending on their delivery and content). Participants were able to develop health literacy skills through both formal and informal learning opportunities that are presented within the time of the programme.

This chapter will draw together the findings from each chapter of the thesis. The first part of this chapter will discuss the key findings and relate them to other models of health literacy. There will also be discussion of the research design and methods used to collect and analyse the findings. Implications of the findings of this thesis will be discussed in the light of health policy and practice, patient education and health literacy measurement and research. Future research directions will be suggested before conclusions of the thesis are presented.

## ***8.2 Discussion of key findings - conceptual development***

In chapter five a range of health literacy categories were set out based on expanded descriptions of health literacy from in the literature review and new categories that were developed from insights into the nature of health literacy based on the analysis of participants' interviews. Thus, health literacy categories developed in this thesis are partly informed by conceptualisations of health literacy from previous research and partly informed by the perspective of patients with a long term condition.

### ***8.2.1 Expanding existing health literacy categories***

#### ***Scientific Literacy***

Zarcadoolas et al. (Zarcadoolas et al. 2006, p.77) refer to scientific literacy as "*skills and abilities to understand and use science and technology, including some awareness of the process of science*". They suggest that scientific literacy is comprised of knowledge of fundamental scientific concepts, an ability to comprehend technical complexity, and an understanding of scientific uncertainty. Such skills described by Zarcadoolas et al., (2006) seem to require an adequate level of science-based knowledge. Few people without a science and technology based education would be able achieve scientific health literacy skills based on their definition. There was little evidence of scientific literacy as described by Zarcadoolas et al. (2006). However, there were areas of science and scientific enquiry of which most



participants could gain some understanding (e.g. human biology and research including drug trials). Thus, the concept of scientific literacy is extended in this study to include the aspects of biological knowledge involved with health conditions and their treatment, the understanding of scientific and medical language, and some ability to interpret research results. Skills in these areas varied from those who admitted that they were not ‘medically minded’ at all (e.g. participant 4XP) to those who had received a medical-based education and had a good understanding of medicine (e.g. participants 4CR and 4EP).

Scientific literacy skills were also important in engagement with research; participants exercised specific skills in critically appraising the quality and relevance of research results of treatments for their condition. Participants in the cardiac rehabilitation group and the diabetes group had the opportunity to develop scientific literacy through the education programmes. For example, they learned about biological processes involved with the aetiology of their condition and how their condition affected biological functioning. Understanding the biology behind their condition helped some cope with their condition, adhere to medication regimes and consequently prevent further complications. Thus, the scientific literacy explained here is a fundamental aspect of health literacy for those who are living with and managing a long-term condition.

#### *Interpersonal health literacy and interactive media health literacy*

Interactive health literacy as explained by Nutbeam (2000, p.263-264) represents “more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances”. However, this dimension of health literacy does not distinguish between different forms of communication. In this thesis there was evidence of distinct health literacy practices, suggesting that interactive health literacy would be best explained when separated into two categories: interpersonal health literacy (communication between two or more persons) and interactive media health literacy (retrieving and interpreting information from media sources such as the Internet).

While both categories are interactive, they require different types of interactive skills. Interpersonal health literacy requires social skills and communication skills in listening to and interpreting more tailored health information, communicating relevant information to health professionals, and forming interpersonal relationships with health professionals. Interactive media literacy requires more critical analysis skills in interpreting and evaluating the relevance and quality of information from independent health information sources. Distinguishing between the two skills sets that are included in these categories may be helpful to the development of health literacy measurements. It was evident in this study that some participants had minimal or no computer skills, and had therefore not developed interactive media health literacy throughout the time of the study and had not been taught skills in an education programme. However, they did develop functional skills and interpersonal health literacy skills and could interpret written material to communicate with health professionals. Although for some participants there may have been connections between their interactive media health literacy and their interpersonal health literacy skills, the two skills sets should remain distinct and be measured separately. Only when separate interactive health literacy measures have been developed can the relationship between the two categories be fully explored.

There was also an apparent link between scientific literacy and interpersonal health literacy. Participants who had more scientific and medical knowledge seemed to exchange more information in consultations and seemed to be more active in decision making (e.g. participants 5CR, 4EP and 5EP). Again, these links can be better explored through the development of separate health literacy measures.

#### *Critical, civic and public health literacy*

There is some overlap between these categories of health literacy and thus they have been grouped together here for discussion. The evidence of these categories was limited in this sample of participants. The social action described by Nutbeam in his definition of critical health literacy was limited to one participant (2CR) who was an organising member of her Diabetes UK branch, held fundraising events and took part in raising awareness of diabetes in her local community. Health literacy as observed in this thesis was developed and practiced for individual benefit rather than for public benefit. Participant 5CR was an example of someone who utilised her health literacy

skills in individual actions to help her assume increasing control over her health status.

There was also little evidence of civic literacy as described by Zarcadoolas et al. (2003). The nearest actions to civic literacy were the distribution of social capital within the diabetes group. There was some evidence of public health literacy as described by Freedman et al. (2009). This was represented by their engagement with information about swine flu and their understanding of the public health risks associated with it. However, most information was dispersed through the media and participants were sometimes sceptical about the quality, value and relevance of the information. What this thesis has shown is that when there are questions over these factors some patients may disengage with information and the perceptions of risk may become distorted.

#### *Functional health literacy*

The concept of functional health literacy was not extended in this thesis. However a range of practices were identified that included functional health literacy skills. Some examples are, reading health information, writing letters to health professionals and organisations for further information, keeping diary records of symptoms or communications with health professionals, note taking in consultations, remembering names of medications and managing a schedule for taking medication.

#### **8.2.2 New dimensions of health literacy**

##### *Food Literacy*

Understanding the link between food and health is important in managing one's health and in particular for the management of some long-term health conditions. Food literacy was identified in this study as an important aspect of health literacy in managing diabetes and cardiac conditions, though mostly by participants with diabetes. The successful management of diabetes relies on managing diet and medication. Understanding how to make appropriate food choices is essential. Based on observations of the X-PERT diabetes programme and the analysis of health literacy practices described by participants in this thesis, food literacy is defined here as '*an understanding of food labels and how food can affect one's health in terms of*

*risks and benefits*'. Leading on from this definition would be *the ability to make food choices that benefit one's health*.

There are no references to the concept of food literacy within the health literacy field. However, there are some references to both food and nutrition literacy that have not been linked with health literacy and thus have not come up in the present literature review. Most definitions of food literacy have been put forward by food and health promotion organisations. For example, food-literacy.org describe it as "*the ability to organise one's everyday nutrition in a self determined and responsible and enjoyable way*" ([www.food-literacy.org](http://www.food-literacy.org)) and wiserearth.org use an adaptation of the IOM (2004) definition: "*the degree to which people are able to obtain, process, and understand basic information about food in order to make appropriate health decisions*". ([www.wiserearth.org](http://www.wiserearth.org)).

There are some references to nutrition literacy in the literature, especially in the area of medical education. Kent (1988) draws on the work of Freire (1970) to suggest that nutrition literacy means more than just understanding the word but also the world. A recent definition of nutrition literacy by Silk et al., (2008) also draws on the IOM definition of health literacy by describing it as "*the degree to which individuals can obtain, process, and understand the basic health (nutrition) information and services they need to make appropriate health (nutrition) decisions*".

The concept of food literacy is not well explained in academic terms and only identified but not fully explored in this thesis. There is scope to develop it further by examining its significance within other health contexts. Furthermore, food literacy should be aligned with the health literacy field and developed as a construct that can be incorporated into the development of health literacy measurement and research.

### *Health Risk Literacy*

The literature on health literacy does not feature the concept of risk literacy in its repertoire. Thus, it does not appear within the literature review chapter in this thesis. There are references to risk literacy in the environmental literature with some links to health. Risk literacy is described by Petts et al. (2003 p. v) in terms of “*the nature and breadth of individuals’ underpinning knowledge relating to science in general, including concepts of uncertainty in risk assessment and the risk issues in particular*”. Petts et al. (2003 p.1) suggest that risk literacy encapsulates: (i) *underpinning personal scientific knowledge relating to science in general, including concepts of uncertainty, as well as the risk issues; and (ii) personal interpretation of this knowledge in the context of everyday experience, and the reconciliation of different sources of information*. Risk literacy within this context better describes knowledge of science and the wider risks in the environment to one’s health.

Zarcadoolas et al. (2006) included “to reduce risks” in their definition of health literacy as an outcome or goal that may be achieved through the development of health literacy over someone’s lifetime. Participants in this study talked about risks and their understanding of risks associated with the development of their condition, maintaining good health, managing medication and lifestyle and environmental risks. Their understandings about risk required retrospective and prospective thinking. As they reflected on past risks they sometimes made connections between their health behaviours and their current health, their chances of inheriting a condition and environmental risk factors. When thinking about the future some participants thought about changes they could make to reduce symptoms and what actions they would need to take to prevent further medical complications to their condition. Those who demonstrated a more developed understanding and more foresight thought about how risks associated with their condition could affect their future life choices. These practices have been incorporated into a category of health literacy that is named in this thesis as health risk literacy: *the understanding of qualitative health risk information, the ability to evaluate it and apply it to one’s own circumstances, and the capacity to make relevant decisions to manage one’s risk*. Health risk literacy as described in this study is important to making lifestyle and treatment decisions when managing a long-term condition. In this thesis the development of health risk literacy

is not an outcome of health literacy (e.g. Zarcadoolas et al. 2006); it is a health literacy process.

### *Distributed health literacy*

Most health literacy research focuses on the ability to engage with information as an individual skill. The role of one's social network in the practice of health literacy is not well understood. In literacy studies the term 'distributed literacy' is used to describe how literacy can be dispersed throughout a group rather than held by one individual. For example, Wagner et al. (1986) describe a scenario where several individuals may each possess only some aspects of literacy, and by combining their efforts they may be more fully literate individuals. Thus a number of individuals may contribute to different aspects of one literacy action (Kouzlin 2003).

Baynham (1995) refers to those who distribute their literacy skills as 'literacy mediators' and defines them as "*a person who makes his or her literacy skills available to others, on a formal or informal basis, for them to accomplish specific literacy purposes*". Papen (2009) draws on the idea of literacy mediators to describe how they may be able to extend and enhance someone's health literacy, and concludes that "health literacy is not solely an individual skill, but that it is a distributed resource available within an individual's social entourage". Literacy mediators help others to understand medical information and may read or write information for them that becomes included in their healthcare consultations (Papen 2009).

This thesis has introduced new knowledge about how *health literacy* is distributed through one's social connections. The term *distributed health literacy* is adapted from Wagner et al's (1986) term *distributed literacy* to explain 'the health literacy abilities, skills and practices of others that help develop an individual's level of health literacy'. Distributed health literacy was dispersed throughout social networks and helped some participants retrieve and process information in order to manage their health and make health-related decisions. Health literacy was an asset that was sometimes disseminated from one person to another (either online or in person) or throughout groups of people (i.e. in families, patient education groups or local and support groups). People who were the source of distributed health literacy are described as '*health literacy mediators*'. This definition has been extended from Papen's (2009)

definition of literacy mediators to account for more recent explanations of health literacy (including those described in this thesis) that extend beyond reading and writing skills.

Some participants had greater access than others to health literacy mediators through their social networks and professional networks. For example, some participants worked in a health related profession and others had access to family members who were health professionals. It seemed that participants who had access to more sources of distributed health literacy (e.g. participants 4CR and 2XP) had a greater understanding of their condition and treatment options. Access to health literacy mediators was, as Papen (2009, p.1 ) describes in her description of literacy mediators; *“an important form of social capital”*. Thus, the findings suggest that the more social capital one has, the more likely they are able to benefit from distributed health literacy. However, this may be dependent on the forms of social capital (e.g. access to health professionals, knowledgeable and experienced advisors, charity and advocacy services and general social support) that are available and the health contexts that people experience.

### ***8.3 The development of health literacy through knowledge practices and actions.***

In chapter six the health literacy Pathway Model was presented. The Model is based on participants' interview accounts that provided evidence of their health literacy practices in various health contexts and the personal and professional barriers that hindered them. Its main features will be discussed here.

#### ***8.3.1 Stage 1: health knowledge***

The first stage in the model is the development of knowledge about health and one's own health concerns. People gain such knowledge through the use of functional health literacy skills when engaging with written health information and through other learning opportunities (i.e. friends and family, interactions with health service providers and media sources such as television and internet sites). Some evidence based models of health literacy place health literacy as a precursor to knowledge and it is implied that an adequate degree of health literacy is necessary to gain knowledge from patient education (Ishikawa and Yano 2008; Paasche-Orlow and Wolf 2007; von Wagner et al. 2008). However, research results about the relationship between health

literacy and knowledge are based on functional health literacy tests (i.e. REALM and TOFHLA). More recent definitions of health literacy incorporate an element of knowledge (Baker 2006). In this thesis health literacy and health knowledge are not exclusive of each other, health literacy does not precede knowledge but is infused with it in a number of health literacy categories.

The relationships between health knowledge and the health literacy skills, practices, actions and health decision-making are reciprocal. For example, knowledge about symptoms may influence the development of self management skills and engagement with further information which in turn may lead to better knowledge of how to manage a condition and in turn also influence self-management and treatment decisions. The outcome of health literacy development in this stage is increased understanding of one's condition and how it should be managed. Thus, increased knowledge can lead on to the development of health literacy skills and practices.

### ***8.3.2 Stage 2: Health literacy skills and practices***

This stage represents the skills and practices that are carried out in the process of enhancing health literacy. Some of these skills include abilities in seeking and engaging with health information through various resources, appraising information, implementing and maintaining self-management regimes, and using self-monitoring devices. Practices are the tasks that put these skills into action. One important point about these skills and practices is that whether or not they were exercised and to what extent that they were practiced were influenced by motivational factors. Whilst some participants did lack some of the skills needed to seek and engage with internet information, others had the skills but chose not to practice them. The link between knowledge and skills is represented in the model as bidirectional. Skills were developed a result of increased knowledge and sometimes the development of skills enabled increases in knowledge, which in turn contributed to the development of further skills and practices. For some participants, knowledge and self-management skills were sufficient and they were not motivated to contribute their knowledge or skills in healthcare consultations. For others, their knowledge and skills were incorporated into more active discussions in their consultations (see next stage).



### **8.3.3 Stage 3: Health literacy actions**

Health literacy actions in this thesis compromise activation within healthcare consultations and involve expressing concerns and desires for information and services, requesting and negotiating medications and contributing to consultations in terms of information exchange (i.e. interpersonal health literacy skills). Some positive outcomes of health literacy actions are access to information and services, changes in medications and participation in decision making. Health literacy actions (stage 3) are developed as a result of developments in health knowledge (stage 1) and health literacy skills (stage 2) that are facilitated by self-directed learning or through consultations with health professionals/educators. Health literacy actions can also feed back to stages one and two and contribute to the development of further knowledge and skills. However, there are personal barriers (heightened emotions, poor mental health, attitude towards information, acceptance of condition and compliance) and professional barriers (i.e. focus on disease, rushed consultations and insufficient, conflicting or inaccurate information) that prevent the practice of health literacy skills and actions and inhibit movement between these three stages.

The identification of these barriers in this thesis may shed light on studies where inadequate health literacy was suggested to influence some patients' understanding of information communicated to them and their motivation to ask questions in consultations (Artinian et al. 2001a; Schillinger et al. 2004; Williams et al. 1998; Williams et al. 2002).

### **8.3.4 Stage 4: Production of options**

This thesis showed how some participants used interactive media health literacy skills to research alternative treatments, which then led to further decision making. They sometimes drew on their knowledge and interpersonal health literacy skills to introduce their findings in their discussions with health professionals (stage 3) and negotiate changes to their usual medications. Sometimes health professionals were open to consider a participant's treatment suggestion and at other times there was more of a negotiation about the suitability of the new option and an element of shared decision making was involved. Some participants reached this stage but their desired options were not made available to them.

### 8.3.5 Stage 5 Decision making

This stage was achieved after engaging with information and building knowledge about options (stage 4). Some informed decisions were independent of healthcare consultations and made individually or with the support of friends and family. Other decisions were made in consultations after options were produced by either the participant and/or the health professional.

Desire for involvement in decision making within consultations was more evenly distributed through both higher and lower educated participants than is reported by Smith et al. (2009). One reason may be that the less educated participants in this thesis had achieved a higher education than less educated participants in the Smith et al study and thus the gap between higher and lower level of education was not great.

Although most highly educated participants desired participation in decision making and wanted involvement in consultations, some were prevented from doing so by their regular health professionals. Equally, some less well educated participants wanted more involvement and experienced similar barriers. Thus, educational attainment (and potentially, social positioning) did not seem to have a direct influence on whether involvement in decision making took place. This study can neither confirm nor refute evidence that those with lower health literacy participate less in shared decision making or informed decision making (e.g. Kim et al. 2001 and Smith et al 2009). Interactive media health literacy skills used at stage three of the pathway model are helpful to producing options (stage 4) and making a more independently *informed decision* (stage 5). However, a combination of interactive media and interpersonal health literacy skills might be helpful to participate in *shared decision-making* (e.g. Charles et al. 1997) (stage 5).

In Kim et al's (2001) study low health literacy (measured at the functional level) was suggested to hinder participants' understanding of computer based information provided as a shared decision making intervention, and consequently there was less participation in decision making. A number of explanations are possible; whilst functional health literacy and knowledge scores were poor, it is likely that limitations among other health literacy categories may have influenced poor knowledge and limited involvement in decision making (e.g. health risk literacy, interactive media

health literacy and interpersonal health literacy). Another explanation is that people who participate less in decision making may be more compliant to advice given by their regular health professional, less motivated to fully engage with additional information and prefer less involvement in any decision making processes. For example, there were participants in this thesis who were more compliant, seemed to have limited knowledge and did not engage in any information seeking or decision making but appeared to manage their condition well. It is not known from this thesis whether those who were more compliant to their health professional's advice were less 'literate' or 'health literate' (as measured by current health literacy assessments) but they seemed to practice fewer health literacy skills and therefore their health literacy may have been less developed than others.

Compliance is recognised in this thesis as a personal barrier to health literacy and participation in decision making. However, the relationship between lower health literacy and compliance is likely to be complex and the direction of the relationship may be difficult to establish. For example, people who are more compliant may have fewer health literacy skills because their compliance may have prevented them developing health literacy skills and practices, or they may be more compliant because they lack health literacy skills in the first place. The health literacy Pathway Model allows for both these scenarios.

#### ***8.4 Contribution to other conceptual models of health literacy***

The main contribution to other models of health literacy from this thesis is the way that health literacy is shown to be a generative construct that develops over time, and is a result of increasing knowledge from engaging with both written and human information sources (i.e. lay sources, educational sources and professional sources). In the Pathway Model devised in this thesis health literacy develops along a trajectory towards a number of milestones that include greater knowledge, improved self management and participation in (informed and shared) decision making. One important feature of the model is that it highlights health literacy as both a process (and set of processes) and as an outcome. The unique value of the health literacy Pathway Model is that it is informed by a dynamic set of health literacy categories that are based on patients' reflections on their health literacy practices which have been developed and maintained over time, and observations of developments in health

literacy over the duration of the study. This extends current descriptions and measures of health literacy that feature it as a fixed and generally dichotomous construct (Davis et al. 1993; Parker et al. 1995) , and incorporates the roles of health contexts, the input of others, and motivators and barriers that affect how health literacy may develop.

*Conceptualising health literacy from the patient perspective (Jordan et al. 2010) [see chapter two, figure 2.9,]*

A recent model of health literacy has been developed based on qualitative research (Jordan et al. 2010). Jordan and colleagues interviewed participants on one occasion and obtained their perspectives at one point in time. Jordan et al. set out seven health literacy abilities related to seeking, understanding and utilising health information within the healthcare setting. These abilities are: knowing when and where to seek information, verbal communication skills needed to describe one's health issues and understand health professionals' responses, assertiveness (linked to successful communication) literacy, retaining and processing information, and skills in applying information. This thesis has provided further examples of when and how people with a long-term condition seek and gain access to health information and has explained how patients engage with information, attempt to evaluate it and place it within the context of their own lives. In the Pathway Model these are recognised as health literacy skills. This thesis has also extended Jordan et al.'s findings by identifying a broad range of health literacy practices that require communication skills and has incorporated them into a concept of interpersonal health literacy.

The Pathway Model helps represent health literacy practices in a more integrated way than Jordan et al. and provides further explanation of the contexts in which participants utilise health literacy. However, some of the factors that affect health literacy abilities in Jordan et al.'s model are supported in this thesis. For example, the role of emotions, fear/anxiety and confidence in health professionals are reflected in the personal barriers identified in this study. Some broader factors identified by Jordan et al. (2010) (i.e. education, socioeconomic factors and cultural influences) were less explored in this thesis and thus are less explicit within the findings.

*Health literacy pathway to involvement in healthcare processes (Ishikawa and Yano 2008a) and causal factors on health outcomes (Paasche-Orlow and Wolf 2007b)*

Other health literacy models reviewed in chapter two are based on a body of cross-sectional research and tend to be based on narrow definitions of health literacy. They portray health literacy as a fixed and dichotomous construct that influences health outcomes via its effect on knowledge, self care and participation in healthcare consultations. In Paasche-Orlow and Wolf's (2007) model linking limited health literacy and health outcomes, health literacy is represented as a causal factor that affects provider-patient interaction (i.e. knowledge, beliefs and participation in decision making), access and utilisation of health care (navigation skills, self-efficacy and perceived barriers), and self-care (i.e. motivation, problem solving, self-efficacy and knowledge/skills). In the Pathway Model health literacy does not influence knowledge at the outset; both health literacy and health knowledge influence each other's development. Health literacy skills and practices are infused with knowledge, and health literacy is not so much a causal influence on these skills and practices but is embedded within them.

Ishikawa and Yano (2008) suggest that Nutbeam's three types of health literacy abilities (functional, interactive and critical) are the first stage on their pathway towards participation in care (including shared decision-making). Knowledge and understanding of a health condition is portrayed as the next stage. Neither Ishikawa and Yano's model nor Paasche-Orlow and Wolf's model allow for the *development* of health literacy. Both models depict the interaction between health literacy and knowledge as uni-directional but do not depict any increases in knowledge or health literacy that may develop as a result of participation in care. In the model developed in this thesis, health literacy is not a precursor to health knowledge, it is infused with it. Health literacy in the Pathway Model is generative and develops as a result of increases in knowledge that have been derived from health experiences, and engagement with information sources and through interactions with a range of other persons (i.e. friends and family, health educators and health professionals).

*Framework for viewing patient physician communication, (Roter, 2005)*

The health literacy Pathway Model devised in this thesis is useful for health professionals to consider when implementing communication strategies. Stages three, four and five of the current Pathway Model overlap with Roter's (2005) Freire-inspired framework for patient-physician communication (see literature review). Health literacy actions (3) resemble the first two stages of '*participation in medical dialogue*' (articulating illness narrative) and '*activation for critical dialogue*' (questioning, information appraisal, negotiation skills). Producing options (4) and informed decision making (5) resemble the final stage '*empowerment for health change*' (making informed choices, assuming responsibility and control of one's health). However, Roter's framework was developed to guide physicians to communicate with low literacy patients. The health literacy Pathway Model developed in this thesis is based on the experiences of patients with a long-term condition and could be applicable across a range of literacy levels.

*Health literacy as an asset (Nutbeam, 2009)*

The Pathway Model lends support to Nutbeam's (2009) model of **health literacy as an asset** and his perspective that "*health literacy is seen as an asset to be built, as an outcome of health education and communication that supports greater empowerment in health decision-making*" (Nutbeam 2009, p2075). Both models allow for improvements in health literacy over time, and through the development of knowledge and skills, which are facilitated by formal and informal learning. Improved health literacy in this thesis was evident in a number of different health literacy categories (e.g. food literacy, health risk literacy and scientific literacy). Some health behaviours and practices were changed as a result of improvements in health literacy skills and participants made choices that they expected to affect their health (e.g. improvements in food literacy led to changes in eating behaviour and more healthy diet). Developments in health literacy enabled some participants to become empowered within some scenarios. However, they sometimes experienced their own personal barriers, or were confronted with barriers created by health professionals that limited their opportunity to become more empowered.

Two stages in Nutbeam's asset model seemed not to be well developed in this thesis and were not reflected in the Pathway Model. These were social organisation and advocacy and engagement in social action for health. The critical consciousness (Freire 1970) and critical health literacy skills (Nutbeam 2000) that are associated with empowerment in the final stage of Roter's model, and also informed Nutbeam's asset model, were however more apparent in participants' personal choices and individual action.

### ***8.5 Developing health literacy through patient education programmes***

Patient education programmes communicate health information to people to enable them to have a better understanding of their condition and manage it more effectively than they may have done previously. As a result of patient education people may sometimes be inspired to make appropriate changes to their lifestyle and behaviours to benefit their health. Another aim of this thesis was to investigate whether health literacy can be developed in group-based patient education programmes. Chapter six detailed how the patient education programmes included in this thesis acted at potential intervention points in the health literacy pathway. The development of knowledge based health literacy categories (i.e. food literacy, scientific literacy and health risk literacy) helped participants self-manage their condition. The development of interpersonal health literacy skills (mainly in the Expert Patient Programme) had some influence on how some participants communicated with health professionals.

Some participants in the patient groups had been learning about their condition and other general health issues over a long period, either through interactions with health professionals or through obtaining health information from the internet and other media and from books and leaflets. However, even those who had managed a condition for a long time and thought that they knew a lot about it at the start of the programme seemed develop their knowledge and new health literacy practices as a result of formal and informal learning at the weekly classes.

One category of health literacy that was not practised by all participants and was not covered in patient education classes was interactive media health literacy. Almost half the participants were not computer literate and even some who had some computer skills and access to a computer lacked the motivation or skills to use the internet to

search for health information. Those who had interactive media health literacy skills were able to access health information in order to check symptoms, seek treatment options, view stories of others with the same condition, interact with others through chat rooms and message pages, view surgery procedures and obtain other health related information. Their findings sometimes helped them build knowledge about their condition, manage symptoms, exchange information in consultations and make decisions about treatments. Those with more developed interactive media health literacy skills combined with interpersonal health literacy skills used the internet to research alternative treatment options and negotiated changes to their regular treatment with a health professional. However, some found it difficult to evaluate and choose the most relevant information.

#### ***8.6 Developing health knowledge and health literacy skills and practices without the patient education programmes***

The aim of using a comparison group in this thesis was to compare how people who do not take part in patient education programmes develop health literacy over time compared with those who do. However, it was more difficult to detect any development of health literacy in the comparison group over the period of data collection.

Participants in the comparison group had learned most of what they knew about their condition prior to entering the research and thus there was less evidence of any developments in health literacy after their second interview. Their development of knowledge and health literacy practices had occurred mostly through consultations with health professionals, talking to family and friends and self-directed learning opportunities. There are a number of other reasons why there was lack of evidence for any development in health literacy in this group of participants during the period of data collection:

- The time period over which the data were collected may have been a factor, participants were followed up 12 weeks after their first interview. Some participants had not had a consultation with a health care professional within this time.



- Some participants had not experienced any changes in their condition or treatment over the period of the data collection.
- Participants in the comparison group differed from participants in the patient education groups in that they had been living with their condition for longer and may have already developed the health literacy skills and practises that they felt they needed to manage their health.
- The perceived learning needs of participants and the level of complexity of the range of conditions in the comparison group may have differed because of the differences in their conditions. Some participants in the patient education groups had more complex conditions compared to those in the comparison group and their perceived learning needs were far greater.

*Reasons for not participating in patient education programmes*

Participants in the comparison group were not motivated to take part in any group based activities. Their preferences for learning about their condition were more self-directed. Reasons were, confidence in their own self management skills (1C and 4C), and one other participant (2C) felt that group support and learning was not always beneficial to her mental health. Participant 1 CR did not participate in a cardiac rehabilitation after his by-pass surgery because he claimed he knew enough about his condition and had his own exercise regime and did not need the support of others to help him recover. Participant 4CR felt that she had a good rapport with her GP and worked with him to manage her condition. Thus, the benefits of self-management education may have been less attractive to her. Furthermore, some people may not feel they need the psychosocial support from programmes like the Expert Patient Programme and cardiac rehabilitation. However, others who have more psychological problems and mental health issues may feel more vulnerable in these programmes. These findings give insights into reasons that people may not have the opportunity to or motivation to participate in patient education programmes.

An element of trial and error was important for some patients in the comparison group and the patient education groups. Participants were sometimes willing to try alternative medicines and complementary therapies to relieve symptoms. If patients

choose to become self-directed learners of health information and seek out alternative treatment methods then adequate health literacy is crucial to their decision-making. Furthermore, they might benefit from some support in their information seeking and communicating their findings to health professionals.

## ***8.7 Discussion of research design and methods***

### ***8.7.1 Sample***

Including participants with a long term condition maximised the potential to identify health literacy practices. The diversity of long-term conditions that were featured in this thesis helped demonstrate a number of different health contexts in which health literacy is important. For example, including patients who had previously experienced a heart event or undergone major heart surgery helped identify the relevance for health literacy in reflecting on past information and health experiences in order to move forward. Including cardiac participants also revealed the importance of emotional factors on the development of health literacy.

Including both newly diagnosed diabetes patients and those who had the condition for a long time enabled the exploration of how long-term sufferers had developed their health literacy up until the programme, how they had developed it over the time of the research and how more recently diagnosed participants had to quickly learn how to manage diabetes. In addition to more recently diagnosed diabetes patients, the thesis included other participants who were more recently diagnosed and more serious cases where diagnosis was still being considered, multiple healthcare professionals were involved, several treatment methods were being tried out or prognosis was unclear (e.g. participants 4CR, 3EP and 5EP). The study showed that for these participants health literacy was crucial for them to develop and maintain an understanding their condition and in planning for the future.

Further strengths of the sample used in this thesis are that it featured participants from a range of educational and social class backgrounds. The sample also included participants who were working or had worked in healthcare settings. There was also a range of participants from other types of employment, some who were retired and some who were unable to work. Two participants were from an ethnic minority group (participant 1EP and 3EP), one of whom (3EP) was an asylum seeker whose first

language was not English. Participant 3 EP also participated in the study as a carer of a child with a long-term condition.

The sample size was small (18) compared to some other qualitative studies of health literacy (e.g. Jordan et al. 2010; Smith et al. 2009) and may be open to criticism. However, the longitudinal element of the study required participants to be interviewed 2-3 times and 18 participants (a total 44 interviews) was a manageable amount of participants considering the time-span available to carry out the project. The patient education classes consisted of 8-12 people and the target number of participants from each group was five. Given the high dropout rate from the Expert Patient Programme and the starting group of eight in the X-PERT diabetes programme, retaining 4-5 participants in the study throughout was a considerable achievement. To increase the overall sample size for similar research in the future, it would be useful to recruit from a number of groups. Future research should also focus on groups of participants in different UK locations and those from different cultural backgrounds to examine variations in the groups of people that attend patient education courses.

Care must be taken in generalising the results and developing theory given the small sample size and heterogeneity of participants, and the range of long-term conditions from which participants suffered. However, the diversity in the sample adds to recognising the different contexts in which health literacy is practiced and developed. Further research with larger sub-groups or a larger sample using a single disease specific group may help confirm or contest some of the theoretical development put forward in this study.

### *8.7.2 Research design*

One unique value of the research design was that it used qualitative methods to produce new health literacy concepts and a conceptual model of how health literacy may develop over time and within different health contexts. No other models of health literacy so far have been based on a combination of observational and longitudinal qualitative data. Thus, the method used in this study was a novel way of generating health literacy concepts. Examining participants' reports of their health literacy-related abilities and observing how they practise health literacy has provided new insights into the range of tasks that include health literacy skills. The analysis of participants' narrative accounts of their health experiences and use of health care

consultations and interactions with health professionals has enabled the identification of the events that motivate people to practice and develop health literacy skills. It has enabled the identification of the environments and people that support the practice and development of health literacy and the personal and professional barriers that are unhelpful to practising and developing health literacy.

The longitudinal element of the research design enabled the student to recognise changes in knowledge and the development of health literacy skills over time (albeit a relatively short time period – 20 weeks for most participants). Studying health literacy over time enabled the identification of what can be achieved through improvements in health literacy from the participants' perspective, rather than outcomes that are usually more objectively measured. One criticism that could be put forward is that the longitudinal element covered an average period of only 20 weeks. Although, the project was time-limited, there were sufficient data to detect some initial behaviour changes, new health literacy practices, social developments (i.e. changes in communication styles) and developments in learning. A longer follow up period would have been better to explore whether such developments were sustained and how health literacy may have developed further, especially for those who were more newly diagnosed (e.g. participants 3XP and 4XP) or had more complex conditions (e.g. participants 5EP and 4CR).

The observation of patient education classes was a useful method of examining how health literacy can be learned and was crucial in identifying the interactive processes that are involved in the transmission of health literacy through both formal and informal learning opportunities.

The comparative element of the research did not work as expected and there were very few comparisons that could be made between the patient education group and the comparison group of participants that had not taken part in any patient education programmes. Extending the period of data collection and matching participants in the comparison group to participants in the patient education group based on their condition and length of time with condition may have made it possible to detect more developments in health literacy in the comparison group and enabled more direct comparisons between the groups.

### *8.7.3 Conceptual development*

The qualitative methodology used here allowed for the health experiences of patients with a long-term condition to inform conceptual development. This enabled categories of health literacy to be extended and described more in terms of what people actually do and what skills they draw upon to manage their health and health consultations. The flexibility permitted in semi structured interviews allowed for the student to investigate what knowledge participants had, which practices they carried out that were similar to existing dimensions of health literacy, and to explore new ideas that could help extend or contest some aspects of health literacy already described. For example, the category of distributed health literacy was developed based on participants' experiences of using others as a health literacy resource. The use of a framework approach to analyse the data has enabled participants' health literacy experiences to be compared and contrasted with existing descriptions of health literacy. This has enabled the modification of current descriptions that are not well described. A questionnaire or measurement tool would have imposed a set of criteria by which to assess health literacy dimensions within a more rigid framework and would have been less helpful in conceptual development.

### *8.7.4 Measurement*

It was not an objective of this study to measure health literacy with a psychometric tool. Thus, it was not possible to estimate the health literacy abilities of participants. The aim was to understand what health literacy is from the patient perspective facilitated by the collection of self-reported abilities. It is possible that some participants may have overestimated or overstated their understanding and knowledge. Thus, the apparent extent of participants' knowledge and understandings was based on the interpretation of the student. There were no objective assessments of knowledge or health literacy to validate the student's interpretations. Given the mismatch between current measurements and diverse definitions, and the level of uncertainty of how knowledge scores and health literacy scores affect self-management behaviours and health outcomes, measuring health literacy or knowledge would have added little to this thesis. Furthermore, the use of self-reported data helped to avoid the sense of embarrassment and shame that is often experienced by some patients who have low health literacy (Parikh et al. 1996). Testing participants could have had a negative effect on their emotions if they had scored low, and may

have affected the level of rapport between the participant and student in subsequent interviews.

#### *8.7.5 Researcher effects*

Throughout the data collection period the student maintained an open mind about whether seeking and engaging with information is something that should or should not be practised and whether it was necessary for participants to understand certain health information. However, it is still feasible that the student may have influenced some information seeking behaviour. Whilst this limitation is accepted, it may not have made a large impact on the research overall. Those participants who were more compliant and did not engage much with information at the outset did not change in their information seeking behaviour. It seemed to be more that the seriousness of the condition, the progression of it and complexities involved with treatments were a strong influence on information seeking.

Participant observation helped diffuse any effects of a perceived gap in knowledge between participants and the student. Participants in the education classes were aware that the student was not medically trained and had no expert knowledge of their condition. Consequently, participants may have been less embarrassed and more open about gaps in their own knowledge and understanding. The student participated fully in the classes and carried out learning activities alongside participants. This helped develop a closer relationship with the participants than would be likely from conducting interviews alone or even non participant observation.

### **8.8 Thesis implications**

#### *8.8.1 Implications for the development of health literacy and management of long term conditions*

The study of health literacy across condition specific contexts produced findings with implications for the development of health literacy for a number of long term conditions. New understandings of how health literacy is developed and practiced in different long-term conditions can help guide the development of strategies to support patients to manage and cope with their condition in ways that benefit their health. Below are some conclusions about potentially important areas for interventions identified in this thesis for the specific conditions.

### *Diabetes*

This thesis has highlighted the importance of scientific literacy and food literacy in managing diabetes. The X-PERT programme was successful in developing both categories and participants benefited from a better understanding of how to interpret and monitor some of their test results, and a better understanding of the importance of food choices and portion sizes in managing blood glucose levels. In order to support patients with diabetes, health care professionals and patient educators should help diabetes patients develop scientific and food literacy and carry out assessments of their understandings and monitor how they incorporate them into their self-care practises. This support is a feature of intervention points one and two of the modified Pathway Model, and can enhance health knowledge (stage 1), health literacy skills and practices (stage 2), and health literacy actions (stage 3) (see figure 7.1).

### *Heart Disease*

An investigation of health literacy practices in patients taking part in a cardiac rehabilitation programme revealed new insights into factors that influence and inhibit health literacy. Two important factors were relevant to cardiac patients; the first is the impact that emotion may have on both the development of health literacy and as a barrier to health literacy. Cardiac rehabilitation participants described their emotional reactions to information and how they sometimes found it difficult to take in information or even engage with information at times when they were anxious or shocked by the severity of their condition and the information that was communicated to them. The more positive outcome of emotional reactions to the severity of the condition in terms of health literacy was that emotion sometimes motivated participants to seek and engage with health information in order to reduce fears and anxieties and to come to terms with the seriousness of recovering from a heart condition and major surgery. Interventions that address ‘managing emotions’ may be useful to help patients cope with their condition.

The second factor identified as important in this group of participants was the role of health literacy in retrospective understandings. One example of this is forming an understanding of information about surgical procedures weeks and months after surgery. Participants had to assimilate new information disseminated through the

education programme with their initial understandings of surgical procedures based on previous information. Learning and understanding about surgical procedures helped some participants come to terms with their condition and made them feel less anxious about the future. Support that could be provided here is a feature of intervention point one of the modified Pathway Model, and can enhance health knowledge (stage 1) (see figure 7.1).

### *Mental health*

This thesis has shown how some participants with mental health problems sometimes find it difficult to engage with or act on health information. Although most mental health patients may have the capacity to seek and understand information, they may suffer symptoms that inhibit their motivation to use that information in ways that may benefit their health and to actively participate in healthcare consultations. Therefore, they are unable to move from stage one (health knowledge) to stages two (health literacy skills) and three (health literacy actions). Motivational based interventions may help activate them to use information to develop self-management skills, make lifestyle changes and discuss treatment options with a health professional. Support that could be provided here is a feature of intervention points two and three of the modified Pathway Model, and can enhance health literacy skills and practices (stage 2), health literacy actions (stage 3) and producing informed options (stage 4) (see figure 7.1).

### *Other conditions*

Other participants in this study had conditions such as arthritis and asthma. Some of the ways they developed knowledge about how to manage their condition was through trying out different therapeutic strategies suggested by their regular health professionals or that they had read about in information leaflets or online. In order to ensure that participants have understood what they have learned and use the information to benefit their health, they may need the support of health professionals to offer them support and guidance with their choices.



### *8.8.2 Implications for the development of health literacy and active involvement in consultations*

The concepts developed in this study help explain the relationship between health literacy and patient involvement in healthcare consultations. The range of health literacy skills identified here and how they are put into practice before and during health consultations are important to the process of healthcare consultations (i.e. whether information is exchanged and understood and whether a patient is involved in any decision-making processes).

#### *Information exchange*

Exchanging information requires interpersonal health literacy skills at the health literacy actions stage of the Pathway Model (stage 3). Depending on the context of the consultation it is likely that a number of health literacy abilities are involved, leading up to and during the process of information exchange. For example, information exchange can involve the ability to retrieve and evaluate the relevance of information to be exchanged, the ability to communicate that information and take part in discussions to resolve a health problem (i.e. shared decision making processes). Deficiencies in these skills may hinder involvement in information exchange and potentially any further involvement in decision-making.

#### *Shared decision-making*

The findings of this study have implications for understanding how health literacy may influence patients' opportunities to participate in decision-making and how they experience it. A number of health literacy abilities across the range of health literacy categories are likely to be necessary for participation in decision making, for example, scientific literacy (e.g. biological knowledge), health risk literacy (e.g. understanding of relevant risks), interactive media health literacy (e.g. seek, engage with, evaluate online information) and interpersonal health literacy (e.g. expressing concerns). Patients' interpersonal health literacy skills in forming a positive relationship with a regular health professional may also influence whether shared decision making is achieved and how it progresses. Thus, if one or more of these health literacy abilities have not been sufficiently developed within the relevant context, patients may be less inclined to participate in decision making or find it more difficult.

The Pathway Model sets out stages towards decision making and thus the health literacy barriers identified in the model have an indirect effect on shared-decision making. The identification of these stages and barriers may help inform healthcare practitioners about how to implement shared decision-making in relevant contexts and how to overcome health literacy barriers. The health literacy categories and the Pathway Model developed here may also be useful in designing and developing shared decision-making interventions. For example, when designing and implementing computer based decision aids, developers need to understand the full range of interactive media health literacy skills and practices that are involved at the health literacy actions stage and how they help patients use health information to generate the necessary knowledge for shared decision-making.

### 8.8.3 Implications for enhancing empowerment

The concept of empowerment within the health literacy field is consistent with improved knowledge, control over one's health and improved choices, and greater involvement in healthcare consultations leading to better health outcomes. In a previous meta-study review by the student (Edwards *et al.*, 2009), empowerment was an outcome of health literacy practices and directly associated with involvement in healthcare consultations. Participants who practiced more health literacy skills and were able to actively participate in health consultations were portrayed as more empowered and those who opted not to become actively involved were described as 'non-empowered'. One argument that can be levelled against participants not being empowered is that empowerment is not a dichotomous concept but more a continuous variable (Anderson and Funnell 2010). Some models of health literacy implicitly or explicitly imply greater empowerment is achieved alongside health literacy outcomes (e.g. Nutbeam, 2008). According to Anderson and Funnell (2010) and Freire (1970), empowerment is both a process and an outcome of patient education (see Chapter 1). Thus, becoming empowered through patient education strategies is an evolving *process* where patients may become progressively more empowered, and the level of empowerment they achieve at a given time or within a given context is an *outcome*. Health literacy is represented in this thesis in the same way. For example, participants became more health literate through patient education and other learning opportunities, and the degree of health literacy they achieved was an outcome of their learning activities.

The Pathway Model has two outcomes in terms of health literacy achievements, these are: (a) an increased knowledge and understanding of how to manage the condition and (b) active involvement in consultations. In this thesis some participants in the study were not motivated to or did not have the necessary skills or opportunity to progress from (a) increased knowledge to (b) active involvement in consultations. Sometimes more compliant participants chose to be more passive in consultations. However, it is likely that the more compliant participants were empowered to the extent that they had enough knowledge about their condition to participate in day-to-day self management decisions to control their condition, but did not exercise the same level of empowerment within in healthcare consultations (Edwards et al. 2009). Some participants seemed to want to be empowered on some occasions but sometimes their level of empowerment was limited by health professionals who did not support their ideas and prevented them from using their health literacy skills to make informed choices.

Although, empowerment is not a feature of the health literacy Pathway Model, health literacy may be a vehicle that drives empowerment through the milestones in the model and thus may run parallel to it. Thus, empowerment is a process within the Pathway Model and may increase as people progress through the health literacy stages. The same barriers that prevent the development of health literacy also inhibit empowerment. Thus, health literacy and empowerment are highly interconnected and both can be viewed as a process and an outcome. For empowerment to be a successful outcome in the health literacy Pathway Model, professional and personal barriers need to be addressed.

#### *8.8.4 Implications for the development of health literacy measurement: different measures at different stages*

It is well known across the health literacy field that current health literacy measures do not incorporate the range of competencies that have been associated with more recent definitions (Kickbusch 2002; Zarcadoolas et al. 2005). Paasche-Orlow and Wolf (2007) suggest that the S-TOFHLA or the REALM should not be used as clinical screening tools and that a broader concept of health literacy needs to be defined to better understand the nature of its relationship to health outcomes.

This thesis has contributed to widening the conceptualisation of health literacy and portrayed it as a multidimensional construct that incorporates knowledge, skills practices and actions. Health literacy is also portrayed as developing over time and within different contexts.

The implications of this view of health literacy are that one overall standard health literacy measure that is administered at one given time point is not appropriate. In order to test the health literacy pathway separate health literacy measures need to be created for each stage in the model. The findings in this thesis support suggestions by Nutbeam (2008a) that a range of health literacy measures are required. However, the recommended range extends beyond functional, interactive and critical health literacy and incorporates the categories of health literacy identified here.

This thesis supports Baker's (2006) conclusion that health literacy is partly knowledge based and recommends that it should be included in health literacy measurement. The findings of this thesis suggest that health literacy and health knowledge develop together and over time through engagement with health information and through formal and informal learning in patient education programmes. Measures of health literacy that draw on an element of knowledge may be appropriate to assess a baseline measure of health literacy; these measures can then be adapted for use at further time points to assess developments in health literacy.

#### *8.8.5 Implications for health outcomes*

Health literacy tests that correlate with poor knowledge tests have been based on functional health literacy. One explanation from appraisals of these types of studies is that it may be that people who have low functional health literacy simply perform poorly on tests. Participants who perform poorly in tests but still manage their condition well and have good clinical results for their blood pressure, glucose level or INR (e.g. Fang et al. 2006; Powell et al. 2007; Williams 1998) may have developed abilities that involve other categories of health literacy such as the new categories identified in this thesis (food literacy, risk literacy and distributed health literacy). For example, their level of food literacy may play a part in managing glucose levels and their level of risk literacy may be involved in their understanding of risks of complications and may inspire people to pay extra attention to foot care and attend

eye screening. Equally, a good level of interpersonal health literacy may help participants understand and adhere to instructions given by their regular health professional(s). Thus, they may manage their condition well because they are following instructions. Compliance may also be stronger if a participant has the interpersonal skills that have enabled them to develop a trusting relationship with a health professional.

Cross sectional studies of the relationship between health literacy and knowledge of long-term conditions and clinical measures of self care do not investigate the role of others in the self-management of long term conditions. One of the unidentified links that may describe why participants with low health literacy and who score low on knowledge tests manage to achieve positive results (e.g. INR, blood pressure and blood glucose) may be their access to distributed health literacy. For example, someone may have the help of family or friends who understand their dietary needs, and manage their diet and cook for them (e.g. participants 1XP and 2CR). Similarly, another person may also have someone who understands their medication regime and organises their medication for them (e.g. participant 2CR).

#### *8.8.6 Implications for policy*

A number of UK policy initiatives have been put forward to address patient education and the quality of and access to health information (Department of Health, 1999; 2001). The implementation of structured diabetes education (X-PERT) and self-management programmes (EPP) have been part of these initiatives. It was beyond the scope of this thesis to evaluate such programmes. However, the conceptual ideas produced by this thesis (including participant interviews and observation of these two programmes) might help provide a framework by which to evaluate their effectiveness in developing health literacy and recommend necessary changes. Given that health literacy is a vehicle for empowerment it should undergo instruction, examination, servicing and annual testing. Thus, patients (who are the drivers of health literacy) need instruction to develop their skills, could undergo tests of those skills, receive regular support in maintaining and developing them and undergo future testing over their lifespan. This set of strategies should be implemented into policy for the development of patient education programmes.

There has also been a policy focus on patient choice in their treatment, and most recently in health care providers (Department of Health, 2004; 2010). Health literacy is a potential requirement for these choices and should be considered when implementing strategies to encourage and support patients to make such choices.

#### *8.8.7 Implications for professional practice and community support*

The identification of how health literacy is facilitated by health and community based social care professionals, emphasises their role as health literacy mediators. It has implications for how health literacy can be facilitated, developed and maintained through interactions with a range of community and hospital based professionals. Professional barriers to health literacy identified in this study can be addressed by developing strategies to educate professionals about the development of health literacy and the range of tasks that require adequate health literacy. The recognition of multiple health literacy categories can help health professionals identify patients' strengths and weaknesses in order to target specific learning needs. By recognising the different dimensions of health literacy, health professionals may be able to adopt a range of methods to communicate health information in a way that best develops patients' understandings of their long-term condition and how to manage it. Furthermore, healthcare professionals may be able to encourage patient involvement in other healthcare processes (e.g. information exchange and informed/shared decision-making).

Whilst there is often limited time in health consultations, the responsibility for identifying health literacy needs and developing health literacy skills should be shared across the range of health care professionals that a person may come into contact with (e.g. GPs, specialists, nurses, physiotherapists, health care assistants and pharmacists). Some participants in this study commented on how GPs, nurses, physiotherapists and pharmacists helped them engage with and understand health information. Nurses and GPs were crucial health literacy mediators in the management of long-term conditions, physiotherapists were important in helping participants understand how to return to usual activities after a debilitating illness event (e.g. heart attack/surgery), and pharmacists were important health literacy mediators in helping people organise, understand and adhere to prescribed medication regimes. Across the wider community, those supporting patients (e.g. social workers, care workers, community

support workers, family and friends) with a long term condition also need to be aware of health literacy in order to offer support and advocate for them when necessary.

#### *8.8.8 Implications for the development and implementation of patient education programmes*

The Pathway Model can be used as a template to guide the development of specific health literacy interventions or to incorporate health literacy development into existing and new patient education programmes. The natural intervention points that were identified in the distribution of health literacy in chapter six compare with intervention points that were identified in the patient education programmes in chapter seven (see figure 7.1.). These can be merged to design specific health literacy interventions that help people: build knowledge based health literacy (food, scientific and risk literacy); build their health knowledge and learn skills to manage their condition; and also aid the development of interpersonal health literacy skills, and provide support for informed decision making. Interventions can be targeted at single or multiple intervention points depending on the context.

Most patient education programmes for long-term conditions already develop knowledge based health literacy skills relevant to one particular condition. However, some programmes can be tailored by prioritising the most relevant categories of health literacy that are important to that condition. For example, food literacy should be a major component in education programmes for conditions where diet is important to self-management (e.g. diabetes). Health risk literacy should be an important part of education programmes for conditions where relapse prevention is important and symptoms can be triggered by the environment (e.g. asthma). Scientific literacy may be important for conditions that require a high degree of symptom management and where medications need to be self-adjusted (e.g. managing INR with warfarin).

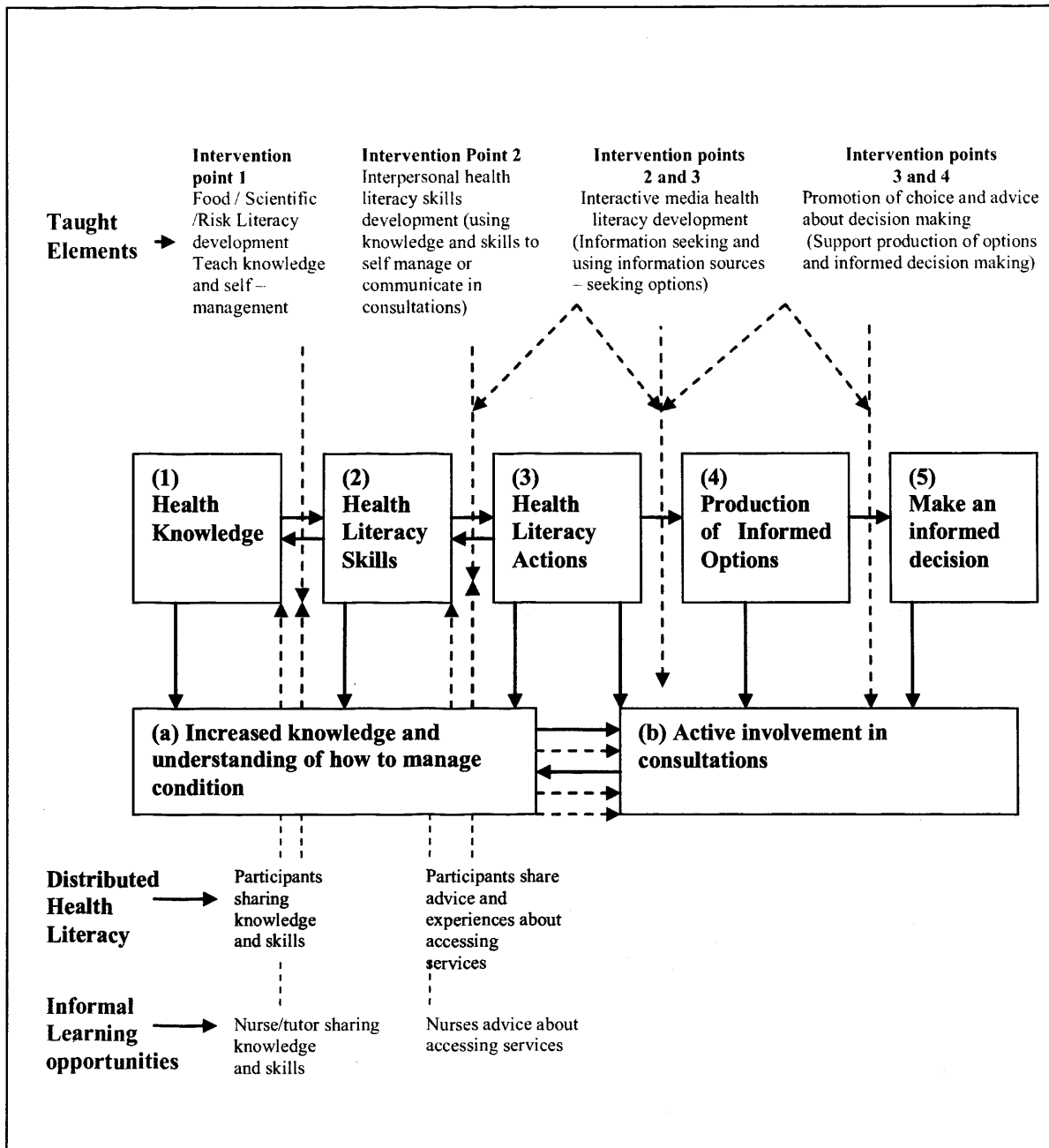
One category of health literacy that was identified as a natural intervention via the distribution of health literacy was interactive media health literacy. Some participants had limited or no computer skills or were not motivated to use the internet to access health information and sometimes used other people to seek and interpret information for them. Some patients could benefit from learning interactive media health literacy

skills in a patient education programme. The programmes featured in this study did not teach interactive media health literacy skills and there are no current patient education programmes known to the student that have implemented elements of interactive media health literacy in their programmes. Thus there is an important gap within patient education programmes that can be filled through designing interventions and implementing elements of interactive media health literacy into their teaching. Furthermore, specific interventions or programmes could be designed specifically to help patients with a long-term condition seek, engage with, evaluate the quality and relevance and use internet based information to better understand and manage their condition. Training in both interpersonal health literacy skills and interactive media health literacy could also help patients incorporate their own research into their discussions with a health professional.

The taught elements in the Pathway Model below (figure 8.1) have been adapted to include interactive media health literacy skills that can be implemented at intervention point two (to teach skills in accessing and evaluating information and use it consultations) and intervention point three (to seek and consider alternative treatment options and incorporate into decision making). Whilst some patients may need an educational intervention at all points in the Pathway Model, others may need more focussed intervention at one or two points in the model (e.g. interactive media health literacy skills at intervention points two and three).



**Figure 8.1 Pathway model with new intervention strategies for patient education**



The model now consists of a complete set of intervention points and a comprehensive set of health literacy categories that can help guide the development of patient education programmes and other health literacy interventions (e.g. computer based decision aids) that can be implemented in isolation or as a set of steps towards informed and shared decision-making.

### **8.9 Future research directions**

The key findings and their implications warrant the development of health literacy research in the following areas:

#### **8.9.1 Measurement**

The development of separate health literacy measures based on the categories identified in this thesis could help researchers to identify isolated health literacy skills and practises that are important in the management of long-term conditions. Such measures would have to be validated in future research. Separate health literacy measures might be useful to unpick some of the complexities involved in studies that have found that participants who have inadequate health literacy and low scores on knowledge tests still achieve good clinical outcomes and manage their long-term condition well. Future research should continue to investigate these complexities in order to inform the development of knowledge based health literacy measures. When validated these measures may be useful in research on health behaviours, health outcomes and health service utilisation. Below are some suggestions on how separate health literacy measures may be useful in research:

Health risk literacy - to assess in relation to preventative health behaviours, medication adherence, clinical outcomes and hospital re-admissions.

-to assess and compare to measures of risk awareness and to compare with measures of health outcomes.

Scientific literacy - to compare with assessments of medication knowledge, to study in relation to adherence to prescribed medications or symptom management.

Food literacy - to understand some of the dietary behaviours of patients who have to adhere to a particular diet in order to maintain healthy cholesterol, blood pressure and blood glucose levels in long-term conditions such as diabetes.

Interactive media health literacy - to assess competencies in seeking, evaluating and using computer based health information.

Interpersonal health literacy - to evaluate patients' competencies in engaging in the communication of health information and to compare against measures of patient involvement in health care consultations (including assessments of shared decision-making processes e.g. Elwyn et al. 2003).

Whilst a one time blanket measure of health literacy may be useful for some research, future research may benefit from the development of separate measures that are context specific and relate to specific health conditions. Future research should also assess potential developments in health literacy over time using longitudinal designs. Measuring health literacy at multiple time points (e.g. every 5-10 years) and comparing results with documentation of health experiences would help gain insights into how health literacy may develop over one's lifetime and help provide a further explanation of influences on health literacy.

### **8.9.2 Health outcomes**

Future research on health literacy and its relationship to health outcomes need to incorporate new measures as suggested in this study. Abilities in specific categories of health literacy may be crucial in managing specific aspects of a condition and achieving specific outcomes. For example, in this thesis food literacy was important in understanding an appropriate diet for patients with diabetes and changes in food choices and portion sizes helped some participants lose weight. Research on health literacy categories and health outcomes is needed to develop health literacy interventions aimed at developing health literacy and at the same time improving health and health outcomes.

### **8.9.3 Patient involvement in consultations**

Future research should also further investigate the influence that specific health literacy categories may have on patient involvement in healthcare consultations. For example, scientific literacy, interactive media health literacy and interpersonal health literacy skills seemed to lead to active involvement in healthcare consultations. In this study, participants that appeared to have a good level of scientific literacy (4CR, 4EP and 5EP) seemed to have better interpersonal health literacy skills and a higher level of involvement in healthcare consultations. However, all three had

worked in health related professions. In order to rule out the effects of professional background as a confounding variable it would be worth investigating the relationship between scientific health literacy and patient involvement in a sample of participants who have not worked in health related professions. Three research questions merit further enquiry:

- Is there a relationship between scientific literacy and involvement in information exchange in consultations?
- Is there a relationship between scientific literacy and participation in shared decision making?
- What is the combined effect of scientific literacy and interpersonal health literacy on patient involvement in healthcare processes and their health?

Further investigation is needed to investigate relationships between interactive media health literacy and interpersonal health literacy, and their combined effect on patient involvement in healthcare processes and their health.

#### *8.9.4 Social networks*

The distribution of health literacy through social networks and the role of others in mediating health literacy are important findings in this thesis. Further research would be useful to fully explore the concepts of ‘distributed health literacy’ and ‘health literacy mediators’. Research questions surrounding the nature of distributed health literacy could be:

- What skills and qualities should health literacy mediators have?
- What categories of health literacy are most important in distributed health literacy?

#### **8.9.5 Patient education programmes**

The health literacy concepts developed in this thesis should be incorporated into the design of patient education programmes and to assess the potential impact on self-management behaviours, engagement in further information seeking and involvement within healthcare consultations. In order to establish whether health literacy has developed through such educational interventions appropriate baseline and post intervention health literacy measures should be implemented that reflect the Pathway Model and the health literacy categories identified in this study. A randomised controlled trial using a control group would be the best method of research to test health literacy before and after educational interventions.

Some of the aspects of health literacy that have been explained so far in the literature were less evident and could not be explained further. This leads questions as to whether concepts such as scientific literacy as described by Zarcadoolas et al., (2006a) and critical health literacy as described by Nutbeam (2000) capture everyday health literacy experiences for most people. Further research in the form of a new health literacy survey that includes these categories may reveal whether these categories are practised in the general population.

#### **8.10 Conclusions**

This study has shown health literacy to be a multidimensional concept that can be both a process and an outcome. Becoming health literate is an ongoing process that develops over one's lifetime and within different health contexts. These contexts are important to the way health literacy develops and what outcomes can be achieved through its development. For some, health literacy helps them reflect, understand, cope with and recover from health events that have occurred in the past, for others health literacy helps them cope with and manage current conditions, and for those who are uncertain about their future health it helps them have some foresight of future risks and helps them prepare and adjust their life plans.

A range of professional and lay health informants or advisors mediate the development of health literacy by sharing knowledge, facilitating learning, contributing their own skills and supporting decision making. However, personal and professional barriers exist that inhibit the development of health literacy and restrict

opportunities to make informed choices. Patient education programmes for patients with a long-term condition can help patients overcome personal barriers and provide them with opportunities to develop both their health knowledge and their health literacy through both formal and informal learning. The findings of this thesis suggest that developing health literacy through formal or informal learning provides patients with the necessary skills that are necessary to make informed decisions that are either independent or made in collaboration with health professionals.

One important goal for policy makers, patient educators and health professionals should be to develop and implement new strategies and interventions to develop health literacy in all patients with a long-term condition. Efforts to test and promote such interventions would need appropriate health literacy measures that incorporate all the dimensions of health literacy and capture changes in health literacy over time. New discoveries about how health literacy was practised and developed by participants in this thesis have informed the development of a conceptual model of health literacy that can be used to aid the development of health literacy interventions. These may be at the individual level (within consultations), the delivery of group-based patient education, health promotion programmes and the development of new and more comprehensive health literacy measures.

Future efforts to improve health literacy across all groups of patients with a long-term condition could help raise health literacy at a public level and enable patients with a long-term health condition to be autonomous and empowered decision makers in their health. In turn, this could contribute to reducing health inequalities. Bringing patients together to develop health literacy at the community level could enable the delivery of structured health education/information and make use of available social capital that helps distribute health literacy through groups of patients.

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## Appendix 1

Letter of ethical Approval.....	283
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Research Ethics  
Committee for Wales

# *REC for WALES*

Chairman/Cardeirydd :  
Dr Gordon Taylor

Ymchwil Ethegau  
Aml-Ganolfan  
yng Nghymru

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Fax No. 029 2037 6824

10 October 2008

Miss Michelle Edwards  
PhD Student  
Department of Primary Care and Public Health,  
Cardiff University, School of Medicine.  
2nd Floor, Neuadd Meirionnydd  
Heath Park  
Cardiff CF14 4XN

Dear Miss Edwards

**Full title of study:** What does health literacy mean to patients and how is it developed  
**REC reference number:** 08/MRE09/54

Thank you for your letter responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Ethical review of research sites**

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying

for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
<del>Participant Consent Form: Patient education group</del> <b>Superseded</b>	1 dated July 2008	
<del>Participant Consent Form: Comparison Group</del> <b>Superseded</b>	1 dated July 2008	
<del>Participant Information Sheet: Patient education group</del> <b>Superseded</b>	1 dated July 2008	
<del>Participant Information Sheet: Comparison Group</del> <b>Superseded</b>	1 dated July 2008	
Letter of invitation to participant	Education Group, version 1 dated July 2008	
Summary/Synopsis	1 dated July 2008	
Covering Letter	signed Miss Edwards	25 July 2008
Protocol	1 dated July 2008	
Application		25 July 2008
Letter of invitation to participant	Patient education group, version 1 1 dated July 2008	
Advertisement	1 dated July 2008	
Interview Schedules/Topic Guides	(1) Interview 1 - Comparison group (2) Interview 2 - Comparison group (3) Interview 1 - Patient Group (4) Interview 2 - Patient Group; all version 1 dated July 2008	
Compensation Arrangements	UM Association certificate of insurance ; expires 31 July 2008	
Letter from Sponsor	signed Mr geraint Jones, Cardiff University	15 July 2008
Investigator CV	Miss Edwards	
Investigator CV	Adrian Edwards	
Investigator CV	Dr Fiona Wood	
Investigator CV	Dr Myfanwy Davies	
Response to Request for Further Information	Letter signed Miss Edwards	
Participant Consent Form: Comparison Group	2, dated September 2008	
Participant Consent Form: Patient education group	2, dated September 2008	
Participant Information Sheet: Comparison Group	3, dated September 2008	
Participant Information Sheet: Patient education group	2, dated September 2008	
Compensation Arrangements	Zurich certificate of insurance : Cardiff University : expires 31 July 2009	

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

**08/MRE09/54****Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



**Dr Gordon Taylor**  
**Chairman**

Email: [corinne.scott@bsc.wales.nhs.uk](mailto:corinne.scott@bsc.wales.nhs.uk)

Enclosures: "After ethical review – guidance for researchers"

Copy to: Mr Matthew Harris

Appendix 2 Information pack for participants in the patient education groups

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Michelle Edwards, BSc, MSc  
PhD student  
Department of Primary Care and Public Health  
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Heath Park  
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CF14 4XN  
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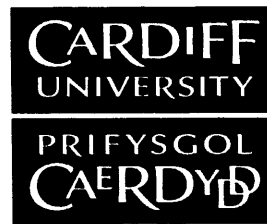
Dear Sir/Madam,

My name is Michelle Edwards and I am writing a PhD on the development of health literacy and investigating its influence of communication with doctors. I will be carrying out my PhD research project during your patient education course. You are invited to take part in the study. I have enclosed an information sheet explaining the details of my study and what is involved. Please take time to read the information sheet before you decide whether you would like to participate. Participation in the study is your decision, and will not affect your place on the course.

Yours faithfully,

Michelle Edwards





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What does health literacy mean to patients and how is it developed?

### Participant Information Sheet

Please read this carefully

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

## **What is the purpose of the study?**

The skills and abilities involved in understanding and using health information and services and managing one's health are known as "health literacy".

We know little of what health literacy means to people and how important it is to them. In this study we want explore peoples' experiences that involve their understanding of health and health services. We also wish to observe how health literacy develops in patient education classes and how people may learn from each other by being part of a group. We also want to find out how people experience communicating with healthcare professionals after they have completed a patient education course. From the results of this study we hope to inform organisers of patient education, health professionals and health policy makers of patients' experiences of health literacy, how health literacy develops and the significance of health literacy for communicating in healthcare consultations.

## **Why have I been chosen?**

We are approaching men and women who have a long-term health condition and have chosen to undertake a patient education course.

## **Do I have to take Part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you decline to take part in this study it will not affect your status on the course. The course will run as normal and the researcher will exclude you from any observations of the course.

## **What will happen to me if I decide to take part?**

If you decide to take part then you will be involved in the study over a period of six months. There are two options: you can take part in the full study which includes interviews and observation of the course or you can just be part of the observation study.

### **Option 1**

If you decide to take part only in the observation part of the study then the researcher will observe your social interactions with others in the group (e.g. instances such as sharing information and advice). The class will not be tape recorded; the researcher may note relevant events during the class and will make more detailed notes after the class.

### **Option 2**

If you would like to take part in the full study I would like to interview you at the beginning of the study, immediately after your completion of the course and

then three months later. I would also like you to be included in an observation of the course (explained in option 1). Interviews will be tape recorded and written up.

### **What about confidentiality?**

All the information gathered from this study will be treated in the strictest confidence and only made available to the research team. Your consent form and the interview tapes will be securely stored in the research office. The computer files containing the interview transcripts and the researcher's observation notes will be stored under a secured password. In order to protect your confidentiality your real name will not be used in any reports of the research and your comments will not be discussed with anyone else.

### **What do I have to do?**

If you would like to take part in the full study you will take part in three 60 minute interviews over a six month period. You do not have to do anything for the observation part of the study; the researcher will just be observing peoples' interactions. However, the researcher may want to ask you a question during a break in the class or afterwards to clarify a point that you may have brought up during the class.

### **Are there any potential risks involved in participating?**

There are no specific risks involved in taking part in this study.

### **What will happen to the results of the research study?**

The results of this research will be included in a PhD thesis and may be published in academic journals. If at the end of the study you would like a summary of the findings and to receive a copy of publications, please contact Michelle Edwards at the address given in the contact information.

### **Who is organising and funding this research?**

This PhD project is funded by a scholarship by the Foundation for the Sociology of Health and Illness and is sponsored by Cardiff University. The principle investigator (PhD student) is Michelle Edwards under the supervision of Professor Adrian Edwards, Dr Myfanwy Davies and Dr Fiona Wood at the Department of Primary Care and Public Health at Cardiff University School of Medicine.

## **What do I need to do now?**

If you wish to take part in the study, please sign the enclosed consent form and indicate by ticking the appropriate box as to whether you want to take part in the observation part of the study only or the full study (including interviews).

**If you wish not to be observed or interviewed let us know by indicating in the relevant box. Your part in the class will not be observed unless you have given consent for us to do so.**

## **Contact for Further Information**

Michelle Edwards, Department of Primary Care and Public Health  
Cardiff University, School of Medicine, 2<sup>nd</sup> Floor, Neuadd Meirionydd,  
Health Park, Cardiff. CF14 4XN

## **Local Information and Support Groups**

Here are the details of some local support groups, if you would like information on a group not listed here please ask the researcher:

Arthritis care: meet in Barry on the second Monday of each month  
<http://www.arthritiscare.org.uk/InyourArea/Wales>  
Contact: 01239 711883

Asthma UK Cymru: provide information and support  
<http://www.asthma.org.uk/wales/index.html>  
Contact: 02920 435 400

Diabetes UK Cymru: provide information and support  
[http://www.diabetes.org.uk/In\\_Your\\_Area/CymruWales2/Wales/](http://www.diabetes.org.uk/In_Your_Area/CymruWales2/Wales/)  
Contact: 029 20668276

British Heart Foundation – Wales: provide support and information  
[http://www.bhf.org.uk/about\\_us/bhf\\_around\\_britain/wales\\_cymru.aspx](http://www.bhf.org.uk/about_us/bhf_around_britain/wales_cymru.aspx)  
Contact: 029 20382368

MIND: offer information and support on mental health  
<http://www.mind.org.uk/mind+in+your+area/regions/cymru/index.htm>  
Contact: Cardiff - 029 20402040  
Vale of Glamorgan - 01446 730792  
Blaenau Gwent – 01495 311445



## CONSENT FORM

Tel: 02920 687168

### What does health literacy mean to patients and how is it developed?

Michelle Edwards, Cardiff University:

Please initial box

1. I confirm that I have read and understand  
the information sheet dated .....(version ....)  
for the above study and have had the opportunity  
to ask questions. ☐
2. I understand that my participation is voluntary and  
that I am free to withdraw at any time,  
without giving any reason. ☐
3. I agree to take part in the observation part of the study only. ☐
4. I agree to take part in the observation part of the study  
and to be interviewed ☐
5. I understand that the interview in which I take part will  
be tape-recorded and that it will be used by researchers  
and the study group. I give permission for the interview  
to be tape-recorded and for the researchers to use this  
recording. ☐

6. I understand that quotes from the observation of classes and my interview may be used in a written report of the study.

Any such quotes would be completely anonymous and could not be linked to me in any way.

☐

7. I do not wish to take part in the study; I wish to be excluded from any observations made during the course.

☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date      Signature

Telephone contact number to arrange an interview  
\_\_\_\_\_

Appendix 3 Information pack for participants in the comparison group

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Michelle Edwards, BSc, MSc  
PhD student  
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Edwardsm6@cardiff.ac.uk

Dear Sir/Madam,

My name is Michelle Edwards and I am writing a PhD on the development of health literacy and investigating its influence of communication with healthcare professionals. I would like to interview people who have a long-term health condition. You are invited to take part in the study. This will involve two interviews, approximately 6 months apart. I have enclosed an information sheet explaining the details of my study and what is involved. Please take time to read the information sheet before you decide whether you would like to participate. If you wish to take part in the study then please return the consent form to me at the above address. Please remember to leave your contact number so that you can be contacted to arrange an interview time and place.

Yours faithfully,

Michelle Edwards





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What does health literacy mean to patients and how is it developed?

## Participant Information Sheet

Please read this carefully

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the purpose of the study?**

The skills and abilities involved in understanding and using health information and services and managing one's health are known as "health literacy".

We know little of what health literacy means to people and how important it is to them. In this study we want to explore peoples' experiences that affect their understanding of health and health services. We also want to find out how people experience communicating with healthcare professionals. From the results of this study we hope to inform organisers of patient education, health professionals and health policy makers of patients' experiences of health literacy, how health literacy develops and the significance of health literacy for communicating in healthcare consultations.

**Why have I been chosen?**

We are approaching men and women who have a long-term health condition. We are interested in how you have learned about your health condition through your own knowledge and experience. Your comments are valuable to the study because they will help us understand the ways in which people come to learn about their own health.

**Do I have to take Part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**What will happen to me if I decide to take part?**

If you decide to take part then you will be involved in the study over a period of six months. We would like to interview you twice, once at the beginning of the six month period and once at the end.

**What about confidentiality?**

All the information gathered from this study will be treated in the strictest confidence and only made available to the research team. Your consent form and the interview tapes will be securely stored in the research office. The computer files containing the interview transcripts will be stored under a secured password. In order to protect your confidentiality your real name will not be used in any reports of the research and your comments will not be discussed with anyone else.

**What do I have to do?**

If you would like to take part in the full study you will take part in two 60 minute interviews over a six month period.

**Are there any risks involved in participating in this study?**

There are no specific risks involved in taking part in this study.

### **What will happen to the results of the research study?**

The results of this research will be included in a PhD thesis and may be published in academic journals. If at the end of the study you would like a summary of the findings and to receive a copy of publications, please contact Michelle Edwards at the address given in the contact information.

### **Who is organising and funding this research?**

This PhD project is funded by a scholarship by the Foundation for the Sociology of Health and Illness and is sponsored by Cardiff University. The principal investigator (PhD student) is Michelle Edwards under the supervision of Professor Adrian Edwards, Dr Myfanwy Davies and Dr Fiona Wood at the Department of Primary Care and Public Health at Cardiff University School of Medicine.

### **What do I need to do now?**

If you wish to take part in the study, please sign the enclosed consent form and indicate by ticking the appropriate box.

### **Contact for Further Information**

Michelle Edwards, Department of Primary Care and Public Health  
Cardiff University, School of Medicine, 2<sup>nd</sup> Floor, Neuadd Meirionydd,  
Health Park, Cardiff. CF14 4XN

### **Local Information and Support Groups**

Here are the details of some local support groups, if you would like information on a group not listed here please ask the researcher:

Arthritis care: meet in Barry on the second Monday of each month  
<http://www.arthritiscare.org.uk/InyourArea/Wales>  
Contact: 01239 711883

Asthma UK Cymru: provide information and support  
<http://www.asthma.org.uk/wales/index.html>  
Contact: 02920 435 400

Diabetes UK Cymru: provide information and support  
[http://www.diabetes.org.uk/In\\_Your\\_Area/CymruWales2/Wales/](http://www.diabetes.org.uk/In_Your_Area/CymruWales2/Wales/)  
Contact: 029 20668276

British Heart Foundation – Wales: provide support and information  
[http://www.bhf.org.uk/about\\_us/bhf\\_around\\_britain/wales\\_cymru.aspx](http://www.bhf.org.uk/about_us/bhf_around_britain/wales_cymru.aspx)  
Contact: 029 20382368

MIND: offer information and support on mental health  
<http://www.mind.org.uk/mind+in+your+area/regions/cymru/index.htm>  
Contact: Cardiff - 029 20402040  
Vale of Glamorgan - 01446 730792  
Blaenau Gwent – 01495 311445



## CONSENT FORM

Tel: 02920 687168

### What does health literacy mean to patients and how is it developed?

Michelle Edwards, Cardiff University:

Please initial box

1. I confirm that I have read and understand the information sheet dated .....(version ....) for the above study and have had the opportunity to ask questions.

☐

2. I understand that the interview in which I take part will be tape-recorded and that it will be used by researchers and the study group. I give permission for the interview to be tape-recorded and for the researchers to use this recording.

☐

3. I understand that quotes from my interview may be used in a written report of the study.

Any such quotes would be completely anonymous and could not be linked to me in any way

☐

8. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

☐

5. I agree to take part in the study.

☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date Signature

Telephone contact number to arrange an interview \_\_\_\_\_

#### Appendix 4 Interview schedules for patient education interviews

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## **Interview 1: Patient Group**

### **Research Question**

What does health literacy mean to patients with a chronic condition, how does this compare to definitions of health literacy.

### **Objective**

Describe the meaning and experience of health literacy skills for patients with a chronic condition and compare this meaning to functional/interactive/critical health literacy and other dimensions.

**Thank you very much for your participation in this research study. Today I would like to talk to you about your views on what you need to understand to manage your health, your experience of health information and your experience of healthcare consultations. This is the first interview of the study, after today you will see me at your course (I will be taking part in the course at the same time as you and making a few observations), I would like to speak to you again shortly after you have completed the course and then once more about three months later. May I remind you at this time your participation in this study is voluntary and you are permitted to withdraw at any time. Today's interview should last about one hour. I would like to record our conversation, so I have an accurate record of what you tell me. Your name will be kept anonymous and anything that you tell me during the course of the study will be kept strictly confidential.**

**Before we start, do you have any questions you would like to ask me?**

Do you have any particular skills in managing your condition?

*[Give an example of a skill and prompt participant to list their skills, explore each skill further if necessary]*

How important is it to you to clearly understand all the things you need to know to manage your health?

*[If they express importance ask why it is important, what does it mean for them?]*

How have you learned the knowledge and skills that you have?

*[Prompt participant to think about how they came to know how to manage their health]*

Are there any things that you don't understand or any skills that you don't have but would like to learn more about?

*[Prompt participant to list, explore item further if necessary]*

How would you prefer to learn these skills?

*[Prompt participant to think about ways that they prefer to learn, e.g. classes, from friends, from doctor, nurse etc]*

**Research Question**

What evidence is there of a range of patients health literacy practices- according to given definitions of health literacy. Do they demonstrate experiences of skills associated with functional health literacy, interactive health literacy, and critical health literacy?

**Objective**

Describe how patients' understandings and abilities concerning their health and their health literacy practices compare with given definitions of health literacy

Do you look for information about your health condition?

What resources do you use?

*[Give examples, internet, magazines TV etc]*

How much do you understand the health information that you have sought about your health condition?

*[What is understood and not understood? What are the reasons?]*

How do you work out which sources of information are reliable?

How often does the information usually apply to your circumstances?

Do you make decisions based on information you have sought about your health condition? *[What decisions?]*

Has any information that you have discovered led you to make an appointment to see your doctor to discuss further? *[Probe for examples]*

Do you know anything about patients' rights and access to medical records?

*[Have you ever accessed your medical records?]*

Do you usually read the information leaflet that comes with your medication?

*[What do you pay attention to, mostly?]*

Do you pay attention to the dosage instructions and the possible risk of side effects?

Do you belong to any support groups or other groups that involve anyone with the same medical condition as you have? *[If yes, probe for details and ask about their experience and how it benefits them]*

**Research Questions**

What are patient's experiences with using healthcare services across different health contexts in relation to their health literacy abilities?

What are the facilitators and barriers to exercising health literacy skills?

**Objective**

Describe how health literacy may affect patients' experiences of using healthcare services in various contexts and identify possible facilitators and barriers.

What healthcare services do you use? (e.g. GP visits, nurse visits, outpatient visits, out of hours service, physiotherapist)

How often do you come into contact with these services?

How would you describe your understanding of how to use or interact with these services? *[Do you know who to make contact with and how to reach them, do you keep regular appointments? Do you know what you need to do if you run out of medication or if there is an emergency? Do you know how to contact a doctor out of hours?]*

Do you ever talk to your doctor about any health information you have discovered?  
*[Probe further to ask what information]*

For example, have you ever brought information to a consultation to show it to the doctor or nurse? *[If no, ask why]*

*[If yes]*

What kind of response do you get?

How much new information do you learn from your consultations with various health professionals?

Do they give information to you in a way that you understand?  
*[If no, why do you think this is?]*

Do you ask your doctor/nurse for more information about your health?  
*[If yes, what kind of information?]*  
*[If no, why not?]*

Do you ever need for your doctor or nurse to clarify any information or advice they have given you?  
*[If yes, what information is that?]*

Have you been involved in making decisions together with a doctor/nurse?  
*[Probe for examples]*

Do you feel that you have enough input into those decisions?



Have you ever had to sign a form to consent to a treatment or procedure? [*Probe for experiences*]

To what extent do you feel you have been able to understand the risks and benefits of the treatment or procedure before you have signed the form? [*What is understood and what is not understood? What are the reasons?*]

Is there anything else that you would like to discuss with me today about your understanding of health information or using healthcare services?

**Thank you for taking the time to talk with me today. Do you have any questions that you would like to ask about what we have talked about today? I look forward to seeing you at the course in a few weeks time. If after today you have any questions about what we have talked about or about your participation in this study here are my contact details.**

## **Interview 2: Patient group**

### **Research Question**

What are patients' views on their experience of participating in a self management or patient education course and what they have gained from it?

### **Objective**

Describe what patients achieve from their experience of participating in a self-management programme (keeping within a focus on health literacy).

**Thank you very much for your participation in this research study.**

**Today I would like to ask you some questions regarding your attitude towards your health and your experience of the course, what you have learned and how you intend to use any new knowledge or skills. The interview should last about half an hour. I would like to record our conversation, so I have an accurate record of what you tell me. Your name will be kept anonymous and anything you tell me will be kept strictly confidential.**

What did you think about your risk of heart disease or any other kind of health problem before you developed a heart problem?

Were you aware of the risk factors and how you might reduce your risk? (diet, inactivity, family history, smoking, stress)

How has that changed since you have taken the course?  
(how much more are you aware of those risks?)

Have there been any changes that you have made to minimise any risk of further problems?  
(any changes in diet, activity...are these changes small changes or big changes? Are these changes for life)

How would you now describe your whole understanding of what has happened and why it may have happened?

(e.g. what may have caused your heart problem, what was done to rectify the problem, and how you need to manage medication and lifestyle to adjust)

How has that changed from the time that you were informed of having a heart problem to now you have completed the course?

How would you describe your experience of taking part in a patient education course?

How important do you think it is to have the opportunity to learn about health information?

What did it mean to you to be in a group of other people who had gone through the same or similar experiences to you?

How have you personally benefited from the cardiac rehab education classes? What have you gained?

What part of the course was most useful to you?

What did you learn that you didn't already know or understand?

Did you learn anything that you might want to discuss further with your doctor?

How important do you think it is to understand medical terminology such medical terms for your condition and symptoms and the names of medication?

How do you intend to use all the information that you have learned through cardiac rehab classes? What does it mean to you to have this new knowledge?

Since you did the course have you looked into any more health information?

How do you think you may have felt if you decided not to take the cardiac rehab classes and hadn't been given the information and knowledge that they have passed on to you?

Is there anything else that you would like to tell me about your experience of the course?

**Thank you for taking the time to talk with me today. Do you have any questions that you would like to ask about what we have talked about?**

**I will be contacting you again in three months time to arrange a time to talk to you about your experiences of communication in healthcare consultations since you completed the course. That will be the final interview of the study. I would like to remind you again that your participation in this study is voluntary and that you are permitted to withdraw from the study at any time. If after today you have any questions you would like to ask me about your participation in the study you can contact me at Cardiff University, here are my contact details.**

### **Interview 3: Patient group**

#### **Research Question**

What are patients' experiences of applying health literacy skills obtained through self-management education to their interactions with healthcare professionals and how does this affect information exchange and shared decision-making in healthcare consultations?

#### **Objective**

Describe the experience of information exchange and shared decision-making in healthcare consultations following participation in self-management programmes

**Thank you very much for your participation in this research study. This is the final part of the study and today I would like to ask you some questions about your experiences of communicating with health care practitioners such as your GP, nurse or specialist over the last 3 months since you completed your course. The interview should last about an hour. I would like to record our conversation, so I have an accurate record of what you tell me. Your name will be kept anonymous and anything you tell me will be kept strictly confidential.**

How much contact have you had with healthcare practitioners since completing the course?

How would you describe your experience of communicating with healthcare practitioners since completing the course? [Is there anything different about the way you communicate since you did the course?]

Have you been able to apply any communication skills you have learned on the course to your consultations? [What skills? What happened? What was the outcome?]

How has your understanding of the information given to you during your consultation been since you completed the course? [What have you understood or not understood? What happened? What was the outcome? How could it have gone better?]

Have you talked to your GP, nurse or specialist about the course and what you have learned?

*[If, no why not?]*

*[If yes, what was their reaction?]*

Have you had the opportunity to ask your GP, nurse or specialist questions about any information you have learned during the course? [How confident are you with discussing new information with your healthcare practitioner?]

Have you been involved in making any decisions about your health or treatment options with your healthcare practitioner? [Can you tell me what happened? What was the outcome?]

Is there anything else you would like to tell me about your communication with your healthcare practitioner since you completed the course?

**Thank you for taking the time to talk with me today. Do you have any questions that you would like to ask about what we have talked about or about the study? If after today you have any questions you would like to ask me about your participation in the study you can contact me at Cardiff University, here are my contact details.**

## Appendix 5 Original interview guides for comparison group interviews

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## **Interview 1:**

### **Research Question**

What does health literacy mean to patients with a chronic condition, how does this compare to definitions of health literacy.

### **Objective**

Describe the meaning and experience of health literacy skills for patients with a chronic condition and compare this meaning to functional/interactive/critical health literacy and other dimensions.

**Thank you very much for your participation in this research study. Today I would like to talk to you about your views on what you need to understand to manage your health, your experience of health information and your experience of healthcare consultations. This is the first interview of the study, after today you will see me at your course (I will be taking part in the course at the same time as you and making a few observations), I would like to speak to you again shortly after you have completed the course and then once more about three months later. May I remind you at this time your participation in this study is voluntary and you are permitted to withdraw at any time. Today's interview should last about one hour. I would like to record our conversation, so I have an accurate record of what you tell me. Your name will be kept anonymous and anything that you tell me during the course of the study will be kept strictly confidential.**

**Before we start, do you have any questions you would like to ask me?**

Do you have any particular skills in managing your condition?

*[Give an example of a skill and prompt participant to list their skills, explore each skill further if necessary]*

How important is it to you to clearly understand all the things you need to know to manage your health?

*[If they express importance ask why it is important, what does it mean for them?]*

How have you learned the knowledge and skills that you have?

*[Prompt participant to think about how they came to know how to manage their health]*

Are there any things that you don't understand or any skills that you don't have but would like to learn more about?

*[Prompt participant to list, explore item further if necessary]*

How would you prefer to learn these skills?

*[Prompt participant to think about ways that they prefer to learn, e.g. classes, from friends, from doctor, nurse etc]*

**Research Question**

What evidence is there of a range of patients health literacy practices- according to given definitions of health literacy. Do they demonstrate experiences of skills associated with functional health literacy, interactive health literacy, and critical health literacy?

**Objective**

Describe how patients' understandings and abilities concerning their health and their health literacy practices compare with given definitions of health literacy

Do you look for information about your health condition?

What resources do you use?

*[Give examples, internet, magazines TV etc]*

How much do you understand the health information that you have sought about your health condition? *[What is understood and not understood? What are the reasons?]*

How do you work out which sources of information are reliable?

How often does the information usually apply to your circumstances?

Do you make decisions based on information you have sought about your health condition? *[What decisions?]*

Has any information that you have discovered led you to make an appointment to see your doctor to discuss further? *[Probe for examples]*

Do you know anything about patients' rights and access to medical records?  
*[Have you ever accessed your medical records?]*

Do you usually read the information leaflet that comes with your medication? *[What do you pay attention to, mostly?]*

Do you pay attention to the dosage instructions and the possible risk of side effects?

Do you belong to any support groups or other groups that involve anyone with the same medical condition as you have? *[If yes, probe for details and ask about their experience and how it benefits them]*



**Research Questions**

What are patient's experiences with using healthcare services across different health contexts in relation to their health literacy abilities?

What are the facilitators and barriers to exercising health literacy skills?

**Objective**

Describe how health literacy may affect patients' experiences of using healthcare services in various contexts and identify possible facilitators and barriers.

What healthcare services do you use? (e.g. GP visits, nurse visits, outpatient visits, out of hours service, physiotherapist)

How often do you come into contact with these services?

How would you describe your understanding of how to use or interact with these services? *[Do you know who to make contact with and how to reach them, do you keep regular appointments? Do you know what you need to do if you run out of medication or if there is an emergency? Do you know how to contact a doctor out of hours?]*

Do you ever talk to your doctor about any health information you have discovered?  
*[Probe further to ask what information]*

For example, have you ever brought information to a consultation to show it to the doctor or nurse?  
*[If no, ask why]*

*[If yes]*

What kind of response do you get?

How much new information do you learn from your consultations with various health professionals?

Do they give information to you in a way that you understand?  
*[If no, why do you think this is?]*

Do you ask your doctor/nurse for more information about your health?  
*[If yes, what kind of information?]*  
*[If no, why not?]*

Do you ever need for your doctor or nurse to clarify any information or advice they have given you? *[If yes, what information is that?]*

Have you been involved in making decisions together with a doctor/nurse?  
*[Probe for examples]*

Do you feel that you have enough input into those decisions?

Have you ever had to sign a form to consent to a treatment or procedure? [*Probe for experiences*]

To what extent do you feel you have been able to understand the risks and benefits of the treatment or procedure before you have signed the form? [*What is understood and what is not understood? What are the reasons?*]

Is there anything else that you would like to discuss with me today about your understanding of health information or using healthcare services?

**Thank you for taking the time to talk with me today. Do you have any questions that you would like to ask about what we have talked about today? I look forward to seeing you at the course in a few weeks time. If after today you have any questions about what we have talked about or about your participation in this study here are my contact details.**

## **Interview 2 comparison group**

### **Research Question**

- a) How might patients with chronic disease who do not attend self-management programmes become more health literate with regard to their condition?
- b) How do these patients experience communication in healthcare consultations (including experiences of information exchange and shared decision-making)?

### **Objective**

To describe the processes by which participants who do not attend self-management programmes become health literate in their condition over time (a six month period) and how they experience healthcare communication (including information exchange and shared decision-making)

**Thank you very much for your participation in this research study. This is the final part of the study and today I would like to ask you some questions about your experiences of communicating with health care practitioners such as your GP, nurse or specialist over the last 6 months. The interview should last about an hour. I would like to record our conversation, so I have an accurate record of what you tell me. Your name will be kept anonymous and anything you tell me will be kept strictly confidential.**

I would like you to think back over the last six months.

Have you learned any new health information over the last six months?  
[What have you learned and how have you learned it?]

Have you learned any new ways of seeking information?  
[What are they? What happened? What was the outcome?]

Have you learned any new skills in managing your health condition?  
[Who did you learn them from?]

Have you had discussions about your condition with another person over the last 6 months? [Who did you talk to and what things did you discuss? How do you benefit from discussing your condition with another person?]

Have you had the opportunity to discuss your condition with another person who has the same condition? [Who? Friend or family member or person you met at a support group? Do you find this be beneficial to you?]

How much contact have you had with healthcare practitioners over the last six months?

How would you describe your experience of communicating with healthcare practitioners over the last six months?

How has your understanding of information given during your consultation been?  
[What have you understood or not understood? What happened? What was the outcome? How could it have gone better?]

Have you had the opportunity to ask your GP, nurse or specialist further questions about any information you may have learned over the last six months?

*[If, no why not?]*

*[If yes, what was their reaction?]*

Have you been involved in making any decisions with your healthcare practitioner?  
[Can you tell me what happened? What was the outcome?]

Is there anything else you would like to tell me about your communication with your healthcare practitioner since you completed the course?

**Thank you for taking the time to talk with me today. Do you have any questions that you would like to ask about what we have talked about or about the study? If after today you have any questions you would like to ask me about your participation in the study you can contact me at Cardiff University, here are my contact details.**

Appendix 6

Interview chart.....317

# *Interview Chart*

	Interview 1	Transcribed	Coded		Interview 2	Transcribed	Coded		Interview 3	Transcribed	Coded	
CR												
1				ME/MD				ME				ME
2				ME				ME				ME
3				ME/MD				ME				ME
4				ME/FW				ME/FW				ME/FW
5				ME				ME				
XP												
1				ME								ME
2				ME/FW				ME/FW				ME/FW
3				ME								ME
4				ME/MD								
EP												
1				ME								ME
2				ME								ME
3				ME								ME
4				ME								ME/MD
5				ME								ME
C												
1				ME								ME
2				ME								ME
3				ME								ME
4				ME								ME



Interviewed



No response



Double coded

Appendix 7 Sample characteristics.....	319
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### *Participant Characteristics*

<b>Participant code</b>	<b>Gender</b>	<b>Age</b>	<b>Condition(s)</b>	<b>Level of education</b>	<b>Profession</b>
<b>1CR</b>	Female	76	Heart surgery	High school	Retired cashier for a pharmacy group
<b>2CR</b>	Male	77	Heart surgery/ diabetes	High School	Retired insurance broker
<b>3CR</b>	Female	73	Heart Surgery	A Level (attended Howells)	Hospital receptionist
<b>4CR</b>	Female	23	Heart surgery	University	Physiotherapist
<b>5CR</b>	Male	54	Heart surgery	University	Draughtsman
<b>1XP</b>	Male	72	Diabetes	High school	Retired vending machine engineer/ part time gardener
<b>2XP</b>	Female	53	Diabetes on insulin	High school	housewife
<b>3XP</b>	Female	52	Diabetes	High school	Learning support worker
<b>4XP</b>	Female	69	Diabetes controlled by diet	College	Part time secretary/retired bank worker
<b>1C</b>	Male	60	Heart surgery	University	Part time Teacher
<b>2C</b>	Female	42	Mental illness	High School/Military	Not in employment
<b>3C</b>	Male	40+	Back Pain	High School	Not in employment
<b>4C</b>	Female	45	Asthma	University	Social Services Manager
<b>1EPP</b>	Female	50	Epilepsy and Osteoarthritis	College	Not in employment was a cook
<b>2 EPP</b>	Male	46	Bipolar disorder	College/University	Construction
<b>3EPP</b>	Female	49	Daughter with chronic illness	College	Asylum seeker/ was teacher
<b>4EPP</b>	Female	66	Bipolar disorder	University	Retired Dietician/Nutritionist - lecturer
<b>5EPP</b>	Female	31	ADEM	Some University	Ex healthcare assistant/social care worker



Appendix 8 Coding

An example of part of a coding summary by group.....322

An example of a coding summary across groups.....324

*Example of part of a coding summary for cardiac rehabilitation participant group*

CR (interview 1)	CR (interview 2)	CR (interview 3)
<b>Accessing services</b>  Asking to see a physio Confident asking to see a doctor Not motivated to see a the doctor	<b>Access to services</b> Would like a phone number to speak to a doctor Doctors are busy Paying a private physiotherapist Personal contact with a health professional	<b>Accessing a service</b> Contact with multiple health professionals Access to nurse support Direct communication  GP services Contacting a pharmacist
<b>Compliance</b>  To medical advice To medication instruction Doing as told Accept doctors information	<b>Ignorance</b>  Ignoring risk Blanking out information Is bliss Not taking risk seriously	<b>Accessing Information</b> Using online media to watch surgery TV news report Research papers Researching condition Research medication options Watching TV documentary about surgery Told more because f knowledge
<b>Decision making</b>  Involvement No involvement Reflect on past decision Social support in making a decision  No brainer decisions Re-evaluate a past decision Shared decision making		<b>Decisions</b>  Confer with another health professional about a decision Decisions about others Re-presenting a decision  Shared decisions Preferences about presentation of decision Shared decisions Informed choices  No brainer decisions
<b>Emotion</b> Fear if don't understand  Fear of information Fear of types of info on net Fear of self-care procedures (medication regime) Fear of the condition Shock about treatment needs/procedures Surprised Making sense of emotions Emotion as a side effect	<b>Emotion</b> Emotion as a side effect Medication regime less scary when you understand Anxiety over medication regime  Shock at having a heart disease Shock for others Unhappy about having to take a medication	<b>Emotion</b> Feeling safe  More you know less frightened Nightmares about surgery  Panicked Scared  Scary subject Shock Terrifying To close to home

**Example of a coding summary for the theme 3- accessing services (across all groups)**

Accessing services	Accessing Advice	Accessing needs	System barriers	Health professional barriers	Health professional facilitators	Personal barriers	Availability
Asking for a service CR EP	To expert advice (Diabetes UK meetings) XP	Asking primary care service for funding CR	Problems accessing services EP C	One way communication EP XP	Interested in condition EP C	Don't know where to look EP	No available information CR EP
Confidence in asking to see a doctor CR C	From doctor friend CR XP	Asking for equipment (monitor) CR XP	Rare condition EP	Focus too much on disease not person EP	GP knows me CR EP C	Not motivated to see a doctor CR	No relevant information CR EP
Paying for a private service CR	Nurses XP C	Asking for notes CR EP		Rushes information EP	GP trusts me CR EP	Belief that doctors are busy CR	
Personal contact with doctor (family friend) CR EP XP	Through employer CR C	Asking for results CR EP		Dismisses information EP C	GP knows my level of communication skills CR EP	Frustration with services EP C	
Contacting multiple health professionals CR EP	Pharmacist XP C	Asking a charity for funding CR		Doesn't listen EP XP C	Deconstructs information from others CR	Depression EP	

Direct communication to health professional CR	Friends/Family C CR EP XP	Asking about research CR C		Conflicting information XP CR		Reliance on health professionals CR EP	
Contacting nurse CR EP		Asking for a medication CR EP C		Doesn't give enough information EP XP		Conflict with health professional EP	
Contacting pharmacist for advice CR EP		Negotiating a treatment option CR EP C		Doesn't make you feel like you have any rights EP		Accepting condition XP	
Contacting charity organisations CR EP				Poor communication skills CR EP XP			
Asking for more time EP				Shows little interest CR EP XP			
Asking for a test CR EP XP							
Asking for a specific doctor CR EP XP							

## Appendix 9

The thematic framework.....	325
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## Thematic Framework

Code	Theme	Description
<b>1.1 Motivation for health literacy</b>	<b>1.1.1 Reduce fear and shock</b>	
	<b>1.1.2 To be prepared</b>	Prepared for progression of disease, complications, symptoms and effects
	<b>1.1.3 Make sense of symptoms</b>	
	<b>1.1.4 Understand procedures</b>	E.g. surgery, treatment
	<b>1.1.5 Seeking options</b>	E.g. choosing a treatment option
	<b>1.1.6 Understanding diagnosis</b>	
	<b>1.1.7 Claims about personality</b>	E.g. enquiring mind, medically minded
	<b>1.1.8 Work in health related profession</b>	
	<b>1.1.9 Build on knowledge</b>	
	<b>1.1.10 Manage symptoms</b>	
	<b>1.1.11 Losing trust in health profession</b>	Want to find out for self
	<b>1.1.12 Become more autonomous</b>	
	<b>1.1.13 Feel empowered</b>	
<b>1.2 Barriers to developing health literacy</b>	<b>1.2.1 Reliance on family</b>	E.g. for medication, computer skills, understanding, communication
	<b>1.2.2 Poor memory</b>	E.g. memory for medication names
	<b>1.2.3 Negative about too much information</b>	E.g. belief that too much information is not good
	<b>1.2.4 Manage anxiety or fear</b>	E.g. avoidance of information to reduce anxieties
	<b>1.2.5 Not skilled in computer use</b>	Can't use computer
	<b>1.2.6 Reliance on health professional</b>	Rely on doctor/nurse as sole information provider
	<b>1.2.7 Claims about personality</b>	E.g. not a curious person
	<b>1.2.8 Tendency to be compliant</b>	E.g. doing as told, doctor knows best
	<b>1.2.9 Blanking out</b>	E.g. avoiding information, ignoring risks, not accepting illness
	<b>1.2.10 Mental health</b>	Feeling depressed, low mood
<b>1.3 What is important to understand</b>	<b>1.3.1 Procedures</b>	Surgery, treatment, managing medication
	<b>1.3.2 Processes</b>	What happened leading up to and during surgery
	<b>1.3.3 Reasons for medications</b>	Why medications are important
	<b>1.3.4 How much medication</b>	Dosage
	<b>1.3.5 Names of medications</b>	
	<b>1.3.6 Effects of medication on the body</b>	Side effects

	1.3.7 Self monitoring	E.g. Blood Glucose
	1.3.8 Progression	E.g. what may happen, complications, future health
	1.3.9 Knowledge of the condition	
<b>Code</b>	<b>Theme</b>	<b>Description</b>
<b>2.1 Functional</b>	<b>2.1.1 Reading medical literature and journals</b>	Condition, reference books, medical dictionary, medical journals
	<b>2.1.2 Reading recipe and food books</b>	Diet, recipe, nutritional
	<b>2.1.3 Reading magazine news papers</b>	health magazines, news paper articles about health condition
	<b>2.1.4 Preferences</b>	Prefer printed information and correspondence
	<b>2.1.5 Writing</b>	Letters, writing off to organisations for information
<b>2.2 Interactive person to person</b>	<b>2.2.1 Discussions with health professional</b>	Treatment options, internet information, new medications, alternative medications/medicines
	<b>2.2.2 Instigate discussions about treatment</b>	Patient initiates discussion
	<b>2.2.3 Preparing information</b>	Prepare information before a consultation
	<b>2.2.4 Communication preferences</b>	Prefer to be honest, direct
	<b>2.2.5 Express concerns</b>	Concerns about a medication
	<b>2.2.6 Discussions with friends and family</b>	Discuss condition, treatments, information,
<b>2.3 Critical</b>	<b>2.3.1 Knowledge of rights</b>	Patient rights and entitlements e.g. access to information, notes
	<b>2.3.2 Accessing medical notes</b>	
	<b>2.3.3 Member of health organisation</b>	Joining a health organisation, charity, community group, support group, research group
	<b>2.3.4 Critical appraisal of health services</b>	Critique health services, health system
<b>2.4 Scientific</b>	<b>2.4.1 Reading about drug trials</b>	Interest in results from drug trials
	<b>2.4.2 Biological knowledge</b>	Knowledge of the body and biological processes
	<b>2.4.3 Medical/scientific language</b>	Using medical and scientific terms
	<b>2.4.4 Interest in Research</b>	On treatments, condition
<b>2.5 Interactive media literacy</b>	<b>2.5.1 Searching</b>	Searching for information online
	<b>2.5.2 Evaluating sources</b>	Evaluating information from internet, TV, radio, news papers
	<b>2.5.3 Applying information</b>	Relating information to self
	<b>2.5.4 Communicating with others</b>	Communication with others using media e.g. forums, email, picture sharing
	<b>2.5.5 Social media</b>	You Tube, Forums, Chat

	<b>2.5.6 TV news</b>	Watching news reports
	<b>2.5.7 Watching surgery footage</b>	Watching surgical procedures similar o same to own surgery
<b>2.6 Civic</b>	<b>2.6.1 Concern about the rights and needs of others</b>	Concern about patient rights and entitlements for all
	<b>2.6.2 Thinking about NHS Money</b>	Thinking about how NHS money is spent
<b>2.7 Risk</b>	<b>2.7.1 Reflect on risks</b>	Past risks
	<b>2.7.2 Family/inherited risk</b>	Family members who have same condition
	<b>2.7.3 Future risks</b>	Thinking about possible risks in the future
	<b>2.7.4 Environmental risks</b>	Thinking about risks in the home, work place, activities
	<b>2.7.5 Unaware of risks</b>	No knowledge or concern over risks
	<b>2.7.6 Ignoring risks</b>	Ignoring risks
	<b>2.7.7 Managing risks</b>	Trying to reduce risks
	<b>2.7.8 Side effects</b>	Thinking about risks presented by medication side effects
	<b>2.7.9 Medication safety</b>	Risks associated with taking medication
	<b>2.7.10 Risk of death</b>	Thinking about the risk of dying, e.g. from condition or surgical procedures
<b>2.8 Distributed</b>	<b>2.8.1 Family/Friend searches information</b>	Another person searches for information online, news papers, books
	<b>2.8.2 Family/Friend manages medication</b>	Another person prepares or organises medications, prescriptions
	<b>2.8.3 Family/friend communicates with health professional</b>	Another person talks to the health professional, in consultations, at hospital, over telephone, by email
	<b>2.8.4 Family/friend manages food</b>	Another person purchases, organises, cooks appropriate food
	<b>2.8.5 Family/friend supports decisions</b>	Another person influences or supports decisions
	<b>2.8.6 Family/Friend takes notes</b>	Another person writes down information in a consultation
	<b>2.8.7 Family Friend offers advice</b>	Another person advises about condition or medication
	<b>2.8.8 Family/Friend involved in care</b>	Another person is involved in caring, e.g. cooking, preparing medications, looking after
	<b>2.8.9 Family/Friend deconstructs medical information</b>	Another person helps explain medical information e.g. a friend or relative in health profession
	<b>2.8.10 Family/Friend present at consultations</b>	Another person attends consultations
<b>2.9 Food</b>	<b>2.9.2 Examining food labels</b>	looking at nutritional information on food labels
	<b>2.9.3 Counting carbohydrate contents in food</b>	counting up carbohydrates or fat contents in daily diet
	<b>2.9.4 Understanding portion sizes</b>	knowledge of appropriate portion sizes



<b>2.10 Cultural</b>	<b>2.10.1 Religious writings about health</b>	E.g. dietary or health advice originating from religious writings, beliefs
	<b>2.10.2 Culturally relevant information</b>	Engagement with information through culturally relevant sources, Quran, Arab television channels, church

Code	Theme	Description
<b>3.1 Accessing Services</b>	<b>3.1.1 Asking for a service</b>	E.g. physio therapy, psychological treatment, nurse care
	<b>3.1.2 Asking to see a doctor</b>	
	<b>3.1.3 Paying for a private service</b>	E.g. physio therapy
	<b>3.1.4 Personal contact with health professional</b>	E.g. friend or relative is a health professional
	<b>3.1.5 Contacting multiple health professionals</b>	
	<b>3.1.6 Direct communication channel</b>	Direct telephone numbers of nurses, consultants, GP
	<b>3.1.7 Contact with a nurse</b>	
	<b>3.1.8 Contact with a pharmacist</b>	
	<b>3.1.9 Contact with a charity organisation</b>	
	<b>3.1.10 Asking for a test</b>	
	<b>3.1.11 Asking for an appointment</b>	
	<b>3.1.12 Asking for a specific doctor</b>	
<b>3.2 Accessing advice</b>	<b>3.2.1 Expert advice at Diabetes UK meetings</b>	
	<b>3.2.2 Doctor friend</b>	Doctor friend offers advice
	<b>3.2.3 Nurses</b>	
	<b>3.2.4 Employer</b>	Health and specific advice from employer or colleagues
	<b>3.2.5 Pharmacist</b>	
	<b>3.2.6 Friends/family</b>	
	<b>3.2.7 Others in group</b>	
	<b>3.2.8 Personal stories on internet</b>	Reading stories of others on internet, internet discussion boards or chartrooms
<b>3.3 Accessing Needs</b>	<b>3.3.1 Asking for funding</b>	
	<b>3.3.2 Asking for equipment</b>	
	<b>3.3.3 Asking for written report</b>	
	<b>3.3.4 Asking for results</b>	
	<b>3.3.5 Asking about research</b>	
	<b>3.3.6 Asking for a medication</b>	
	<b>3.3.7 Negotiating a medication/treatment</b>	

<b>3.4 System barriers to Access</b>	<b>3.4.1 Problems Accessing services</b>	E.g. getting a nurse to come out, making appointments, seeing a specialist
	<b>3.4.2 Limited information available</b>	
<b>3.5 Health professional barriers</b>	<b>3.5.1 Focus on disease</b>	
	<b>3.5.2 Rushed information</b>	
	<b>3.5.3 Dismissed information</b>	
	<b>3.5.4 Not listened to</b>	
	<b>3.5.5 Not enough information given</b>	
	<b>3.5.6 Poor communication</b>	
	<b>3.5.7 Little interest</b>	
	<b>3.5.8 Conflicting information</b>	
<b>3.6 Health Professional Facilitators</b>	<b>3.6.1 Interested in condition</b>	
	<b>3.6.2 Health professional knows me well</b>	
	<b>3.6.3 Knows my level of knowledge</b>	
	<b>3.6.4 Deconstructs information</b>	E.g. explains information given by other health professionals
<b>3.7 Personal Barriers</b>	<b>3.7.1 No knowledge of information sources</b>	
	<b>3.7.2 Not motivated to see a doctor</b>	
	<b>3.7.3 Belief that doctors are too busy</b>	
	<b>3.7.4 Frustration with services</b>	
	<b>3.7.5 Depression</b>	
	<b>3.7.6 Reliance on others</b>	E.g. family members
	<b>3.7.7 Conflict</b>	With health professionals or reception staff
	<b>3.7.8 Accepting condition</b>	
	<b>3.7.9 Not computer literate</b>	
	<b>3.7.10 Limited knowledge</b>	
	<b>3.7.11 Newly Diagnosed</b>	

Code	Theme	Description
4.1 Medication knowledge	4.1.1 Information on effects	Looking up side effects, making sense of side effects
	4.1.2 Medication regime	
	4.1.3 How medication works	How the medicine effects parts of the body, what it is doing, risks/benefits
	4.1.4 Alternative options	What other medication options there are or alternative medicines, therapies
	4.1.5 Developing knowledge	Learning about medications
	4.1.6 Knowledge of how one drug affects another	
	4.1.7 Knowledge of insulin	How insulin works, how to manage insulin
4.2 Managing medication	4.2.1 Adjusting dosages	Altering dosage
	4.2.2 Organising a regime	Preparing, organising prescriptions, medications, doses
	4.2.3 Changes	Managing and monitoring changes
	4.2.4 Adjusting to new medications	
	4.2.5 Competent in managing medication	
	4.2.6 Managing with food	Managing medication with food and meal times
	4.2.7 Generating ideas about medication regime	Ideas about ways of taking medications
	4.2.8 Adjusting to insulin	
	4.2.9 Diabetic control	Talk about control of blood sugars
4.3 Knowledge of the body	4.3.1 Symptom awareness	Recognising symptoms
	4.3.2 Effects of medication	How medication works in the body
	4.3.3 Effects of surgery	On the body
	4.3.4 Recognising changes	Changes in the body or feeling
	4.3.5 Limitations	Disabilities and limitations in movement or memory
	4.3.6 Want to know what's going on with body	
	4.3.7 It's my body	
	4.3.8 Effects of illness on the body	
	4.3.9 Effects of medication on the body	
4.4 Self care	4.4.1 Not reliant on health professional	
	4.4.2 Healthy eating	E.g. food choices, cooking methods
	4.4.3 Exercise regime	
	4.4.4 Self-monitoring	E.g. blood glucose, INR
	4.4.5 Self-reliance	Not relying on others to provide care
	4.4.6 Planning daily activities	E.g. going out, in the house, cooking

<b>4.5 Keeping records</b>	<b>4.4.7 Managing symptoms</b>	E.g. pain
	<b>4.5.1 of Medications</b>	Writing a list of medications and dosages
	<b>4.5.2 of Results</b>	E.g. test results from doctor, glucose level, INR level
	<b>4.5.3 of Communication</b>	E.g. letters, notes, conversations with health professional
	<b>4.5.4 of Symptoms</b>	Diary of symptoms or changes in body or feeling
	<b>4.5.5 of Appointments</b>	Diary of appointments
	<b>4.5.7 Media information</b>	keep news paper articles
	<b>4.5.8 Information</b>	file bits of information, booklets, leaflets, news letters
<b>4.6 Managing people</b>	<b>4.6.1 Multiple health professionals</b>	GP, Consultants, Nurses, Physiotherapists, Psychologist
	<b>4.6.2 Organising appointments</b>	Checking appointments
	<b>4.6.3 Checking advice with other professionals</b>	Cross checking advice, asking for opinion

Code	Theme	Description
<b>5.1 Emotion</b>	<b>5.1.1</b> Fear of not understanding	Not understanding the condition, processes (surgery), medications
	<b>5.1.2</b> Fear of being misled	E.g. by health professional or internet information
	<b>5.1.3</b> Fear of medication regime	E.g. complicated medication regime
	<b>5.1.4</b> Fear of condition	
	<b>5.1.5</b> Shock	E.g. at event, surgery needs
	<b>5.1.6</b> Making sense of emotions	
	<b>5.1.7</b> Reducing fear	
	<b>5.1.8</b> Panic	
	<b>5.1.9</b> Scared of information	E.g. information too graphic, talk about death
	<b>5.1.10</b> Feeling depressed	
	<b>5.1.11</b> Fear of insulin/injecting	
	<b>5.1.12</b> Fear of complications	E.g. complications of diabetes, heart surgery
	<b>5.1.13</b> Fear of death	
<b>5.2 Readiness</b>	<b>5.2.1</b> Not ready for information	
	<b>5.2.2</b> Ready to engage with information	
	<b>5.2.3</b> Ready to accept condition	
	<b>5.2.4</b> Ready to return to daily life	
<b>5.3 Reflection</b>	<b>5.3.1</b> Previous health	
	<b>5.3.2</b> Previous lifestyle	
	<b>5.3.3</b> Past decisions	
	<b>5.3.4</b> Self in relation to others	
	<b>5.3.5</b> Previous knowledge	
	<b>5.3.6</b> Previous fitness	
	<b>5.3.7</b> Previous diet	
	<b>5.3.8</b> Why me	
<b>5.4 Life</b>	<b>5.4.1</b> Illness effect on life plans	E.g. returning to work, having a family, holidays etc
	<b>5.4.2</b> Moving on with life	
	<b>5.4.3</b> Overcoming barriers	E.g. career progression, getting out and about, travelling, daily tasks
	<b>5.4.4</b> Getting back to normal	
	<b>5.4.5</b> Planning a future	E.g. career, children

<b>5.5 Support</b>	<b>5.4.6</b> Thinking about illness and everyday life	E.g. how illness affects daily routine
	<b>5.4.7</b> Building confidence	
	<b>5.5.1</b> Sharing experiences	With others
	<b>5.5.2</b> Being in a group	
	<b>5.5.3</b> Talking to others	About condition
	<b>5.5.4</b> Comparison with others	Compare symptoms, surgery, medications, health status
	<b>5.5.5</b> Nurses supportive	Support from nurses at home or in the hospital or general practice
	<b>5.5.6</b> Permission to participate in activities	E.g. going out after surgery, taking exercise, doing things in the home
<b>5.6 Adjustments</b>	<b>5.5.7</b> Family and friends	
	<b>5.6.1</b> Lifestyle	Activities, exercise
	<b>5.6.2</b> Diet	Food choices, portions, cooking methods
	<b>5.6.3</b> Career	Development, change environment, avoid risks
	<b>5.6.4</b> Activities	Physical activities, sport, leisure activities
	<b>5.6.5</b> Coping	Coping with condition
	<b>5.6.6</b> Medication	Adjusting to a new medication or changes in medication
	<b>5.6.7</b> Building confidence	confidence to go out, manage medication, activities

Code	Theme	Description
<b>6.1 Decision making</b>	<b>6.1.1</b> Desire for involvement	
	<b>6.1.2</b> Reflect on a past decision	Re-evaluate decisions, justify decisions
	<b>6.1.3</b> Social support	Support from family, friends
	<b>6.1.4</b> Difficult decisions	
	<b>6.1.5</b> No-brainer decisions	Decisions that are easy and very serious
	<b>6.1.6</b> Shared decisions	With health professional
	<b>6.1.7</b> Confer with other professional about decision	
	<b>6.1.8</b> Presentation of decision	
	<b>6.1.9</b> Self-management decisions	Daily decisions about medications and activities
	<b>6.1.10</b> About risks	Taking a medication, activities
	<b>6.1.11</b> About medications	Altering doses, stopping a medication
<b>6.2 Barriers to decision-making</b>	<b>6.2.1</b> No desire for involvement	
	<b>6.2.2</b> Confusion	Confusion over why decision (choice) was given
	<b>6.2.3</b> Poor presentation of decision	
	<b>6.2.4</b> Reliance on doctor	Rely on doctor to make decisions
<b>6.3 Choices</b>	<b>6.3.1</b> No desire for choice	
	<b>6.3.2</b> Active interest in choice	
	<b>6.3.3</b> No experience or opportunity for choice	Never give a choice
	<b>6.3.4</b> Seek own choices	Seek medication options, treatments
	<b>6.3.5</b> Own informed choices	
<b>6.4 Compliance</b>	<b>6.4.1</b> To medical advice	Doing whatever doctor advises with little question
	<b>6.4.2</b> Accept health professional as information provider	
	<b>6.4.3</b> Accept health professional as decision maker	
	<b>6.4.4</b> Trust	Trust health profession or specific professionals
<b>6.5 Influences on decisions</b>	<b>6.5.1</b> Partners/family	
	<b>6.5.2</b> Online information	Finding out information which influences a decision
	<b>6.5.3</b> Experiencing side effects	
	<b>6.5.4</b> Others experiences	Reading stories or listening to others
	<b>6.5.5</b> Advice from others	Advice from friends or other people with the condition



<b>6.6 Exchanging information</b>	<b>6.6.1</b> Discuss media or internet information	
	<b>6.6.2</b> Discuss medication options	
	<b>6.6.3</b> Discuss results	Tests, self-monitoring
	<b>6.6.4</b> Discuss diagnosis	Discuss what the problem might be, what diagnosis means
	<b>6.6.5</b> Brining information to a consultation	

<b>7.1 Changes</b>	<b>7.1.1</b> Food	Choices, diet, portions
	<b>7.1.2</b> Exercise	
	<b>7.1.3</b> Knowledge/expertise	
	<b>7.1.4</b> Lifestyle	
<b>7.2 Learning</b>	<b>7.2.1</b> Communication	Communication skills
	<b>7.2.2</b> Condition	
	<b>7.2.3</b> Self-care	
	<b>7.2.4</b> From course	
	<b>7.2.5</b> From others	
	<b>7.2.6</b> Self-directed learning	E.g. from books or internet
<b>7.3 Developments over time</b>	<b>7.3.1</b> To come to terms with condition	
	<b>7.2.2</b> To learn about condition	Learn and understand
	<b>7.2.3</b> Building a relationship with health professional	

## Appendix 10

Example of a chart used in the framework approach (theme 1 – health literacy categories, cardiac rehabilitation participants, interviews 1-3) .....338

Framework chart for health literacy categories – cardiac rehabilitation group

Rehabilitation								
Cardiac								
2. Health Literacy Categories								
Participant (interview)	2.1 Functional	2.2 Interactive (person to person)	2.3 Critical	2.4 Scientific	2.5 Interactive media	2.6 Civic	2.7 Risk	2.8 Distributed
Participant 1 (1)							If it had exploded.. it explodes apparently. If it had in the wrong place even to a fraction it would have been..that's it. (2.7.10)	
Participant 1 (2)							<p>Quite a number of the family um it had all been through stress now that's why I think that I had this attack. (2.7.1, 2.7.2)</p> <p>I've never really been very very conscious of it I don't know whether I've purposely blanked it out or not I don't know (2.7.1, 2.7.5)</p>	
Participant 1 (3)		he was talking about what he was going to do this, that and the other thing and I just said I'm sorry I just can't understand you (2.2.1)			But I really do think it is dreadful the way it's covered. Somehow or other they have become hysterical and that doesn't do anybody any good. (2.5.2)		they said that if they put the stent in because it explodes if it was once again a fraction out it would have been curtains (2.7.10)	He explained it to John and to Cliff and then they explained it to me and that was fine that's all I wanted (2.8.3)

Framework chart for health literacy categories – cardiac rehabilitation group

Participant (interview)	2.1 Functional	2.2 Interactive (person to person)	2.3 Critical	2.4 Scientific	2.5 Interactive media	2.6 Civic	2.7 Risk	2.8 Distributed
Participant 2 (1)		Oh yeah, if I did have any problem I'd go down to the doctor and tell him and I you got a bit of faith in them you see. (2.2.5)						
Participant 2 (2)							Well um not really but smoking did come into to it but I haven't smoked for twenty years.(2.7.1)	she gave me a print-out and she said oh show that to the doctor and tell him what it is (2.8.1)  she knew the surgeon she could have a professional chat with him. (2.8.3)
Participant 2 (3)								My wife is pretty good with the pills if she wasn't there I'd probably be not indifferent but lackadaisical (2.8.2)

Framework chart for health literacy categories – cardiac rehabilitation group

Participant (interview)	2.1 Functional	2.2 Interactive (person to person)	2.3 Critical	2.4 Scientific	2.5 Interactive media	2.6 Civic	2.7 Risk	2.8 Distributed
Participant 3 (1)								
Participant 3 (2)								
Participant 3 (3)		I think when you go to the doctor that's fine I think you have got to take time then to ask him questions if you need to. You do hear a lot of people come away from the doctor and then find.... And then I'll say why did he say that and oh well I don't know I didn't ask him. When you are there you have got to ask the questions then haven't you really? (2.2.1)						My daughter actually went on the internet and found out more about it and as well as anybody else she was saying well it says on the internet the benefits outweigh the risks um. (2.8.1, 2.8.5)

Framework chart for health literacy categories – cardiac rehabilitation group

Participant (interview)	2.1 Functional	2.2 Interactive (person to person)	2.3 Critical	2.4 Scientific	2.5 Interactive media	2.6 Civic	2.7 Risk	2.8 Distributed
Participant 4 (1)		<p>Um I find they...they explain more if you ask more very definitely. I mean they knew I was slightly medically minded because I'm physio so when I started asking more questions they respond more medically. (2.2.1)</p> <p>Um I did a little bit of research before I went to see the surgeon and said so I know there's a pig valve and a mechanical valve um what can i...you know what's going to happen with me. What are the options but I didn't. (2.2.2)</p> <p>they gave me this full on half an hour spiel about what I needed to do for six weeks um then they kind of leave you be and you loose your way a little bit and you don't know what's going on so I've had um you know the cardiologist and the cardiac surgeon as well are really good and meetings telling me what to do um if I've had any problems (2.2.1)</p> <p>say what are you worried about today..what are you terrified about... he was very good at putting my mind at rest and getting me through another day (2.2.7)</p>		<p>I haven't got any coronary heart disease ..um I did have a heart disease but it was idiopathic and it was to do with inflammation um and it's all gone. (2.4.2, 2.4.3)</p>	<p>I just looked it up online you know all these ophthalmology websites and all this kind of stuff (2.5.1)</p> <p>I did a little bit of research before I went to see the surgeon and said so I know there's a pig valve and a mechanical valve um what can i...you know what's going to happen with me., what are the options (2.5.1)</p> <p>you always find people that is in a similar position so there's a guy that had a valve put in 2 days after I did... and it's been brilliant talking to him and comparing notes (2.5.3, 2.5.4, 2.5.5)</p> <p>He has an online webcam just coming on oh look week 4 it's like this and week 5 and this is what I'm doing this is what...i've been talking to him and we've been emailing back and forth. (2.5.4, 2.5.5)</p> <p>having the GUCH online and being able to say...honestly being able to just put a question out there and say ...when I breathe in why does it sound like my chest is popping ..(2.5.4, 2.5.5)</p>		<p>he really went so the risks are 1 in 20 of you know and there is a risk of death its very low um and this is what would happen and blah blah blah and I just wanted him to skip through everything and not think about what could happen um he really did explain everything and then said look I haven't lost anyone yet and you know all this stuff but um with the surgery it was .... (2.7.10)</p> <p>Because you are on bypass you are a zombie for 4 hours and you know the risk of clotting and the risk of brain death and all that kind of stuff um and infection afterwards but they went through..they really spent time they spoke to the whole of my family as well they had a good twenty minutes to sign the consent with the anaesthetist and the surgeon (2.7.10)</p>	<p>My parents are really good as well they um...they've done a lot with my grandma who is quite ill and they learned very quickly they need to write things down so every time I had ward rounds and I have 4 or 5 a day and every time I've gone for an appointment ...I don't do it myself but who ever is with me will write things down. And so we can remember what they've actually said because I never remember and when you are there and they are saying really scary things you don't .....you don't remember (2.8.6, 2.8.10)</p>

<p><b>Participant 4 (2)</b></p>	<p>I've gone and read text books, I've been online I've read journals (2.1.1)</p>	<p>went and talked to the doctor and said I'm really not happy and by the end of it was clinging on going you have got to get me off these drugs they are really too painful and he said ok then we'll take you of them and we'll try something else and you can tell me if it doesn't (2.2.1, 2.2.2, 2.2.5, 2.2.7)</p> <p>I went to see a specialist in London who works with the team here that I'm under and he was really good and I had a lot of questions for him so I asked him everything I saw him...I was in hospital for a week so we did a lot of talking so every time we had a test come back he would discuss it and my parents would write it down (2.2.1, 2.2.5)</p>		<p>Um I had evasculitis so the walls of my aorta became destroyed and they expanded and the disease progressed down to my valve and expanded and ate my valve so they had to replace the whole lot and that's why I didn't have blood pressure so I was fainting and dizzy and didn't have exercise tolerance (2.4.2)</p> <p>I've had multiple MRI's CT scans PET scans lots more histological tests and so it's a rare condition and I'm the 4th person in the UK they have three other living no two other living people at the moment that have it. Um just like arthritis just like evasculitis but specifically affects the ascending aorta. So it doesn't go beyond the arch or the descending area that just goes up to the brain. (2.4.2, 2.4.3,)</p>			<p>Everything in my life is a lot more considered. (2.7.3, 2.7.7)</p> <p>just going off mountain biking there is big risks involved now if I fall over I fall off down a hill I could really severely bleed because I'm on the warfarin and internal bleeding and things like that so everything I do there is more of an element of risk (2.7.4, 2.7.7)</p> <p>It reduces my immune system so I can cope with colds, coughs, flu and things. I work in the health system I'm going to get ill all the time. (2.7.4)</p> <p>I'm not going skiing with my parents anymore because skiing is too much of a risk.(2.7.4, 2.7.7)</p> <p>I can't work in certain fields where I'm more exposed to risks so I can't have somebody coughing up into a pot near me because I have no... a reduced immune system so I would just constantly get ill (2.7.4, 2.7.7, 2.7.10)</p>	<p>I was in hospital for a week so we did a lot of talking so every time we had a test come back he would discuss it and my parents would write it down (2.8.6, 2.8.10)</p>
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Framework chart for health literacy categories – cardiac rehabilitation group

<p><b>Participant 4</b> <b>(3)</b></p>		<p>I did make my voice heard and said look I really don't want to do this anymore (2.2.1,2.2.5)</p> <p>.... I went back to my doctor and said I really don't to be on the tablets and I did some research and I found a liquid aspartame that I can by from Boots (2.2.1, 2.2.2, 2.2.5)</p> <p>.....I started reminding my rheumatologist two moths ago because I now he takes some time and I mentioned it I need time to book off work but I know he won't get it sorted and the thing is I need it to be done. (2.2.1)</p> <p>I've chatted to my rheumatologist at the hospital and said oh have you seen patients with this? What do you see regularly?(2.2.1, 2.2.5)</p> <p>I'm now a lot more direct and because I have some knowledge and I have some medical understanding I don't like to be patronised by doctors when they say "oh you have got a bit of an inflamed aorta" I go no actually I've got this I know my CRP level is rising and my ESR is ok and they go ok and if I want something I ask for it. (2.2.1, 2.2.4)</p> <p>This time I went and said I need this drug it stops me from becoming anaemic and my consultant has cleared it for a year so you need to give me more of it no please or thank you just. (2.2.1, 2.2.2, 2.2.4,2.2.5)</p>		<p>I don't know if I'm meant to know but I do know that my cardiologist is running it so next time I see him I'm going to tackle him about it. it's a very exciting new drug that replaces warfarin it hasn't got the side effects so I can drink alcohol not that I want to terrible but I miss a glass of wine every now and then and I don't have to constantly change my levels so at the moment I'm doing 6.5mg next day I've got to take 7 depending on what I eat at the moment it tends to be quite steady but my INR still fluctuates my level whereas on this drug I would take one pill a day and it does the same as long as my INR is fine (2.4.1)</p> <p>I'm on blood thinners and because I'm female it makes you bleed and I have a lot of hormones which I have to take to stop me bleeding now most of the time that is balanced and I make a very careful how much more I'm going to take to balance it So it's a really complex system but I have got very good at maintaining there in my body. 2.4.2,2.4.4)</p>	<p>I did some research and I found a liquid aspartame that I can by from Boots (2.5.1, 2.5.3)</p> <p>I go right away and try to look stuff up but everything I found was detailed and he had told me so with the vasculitis trusts and things like that just put in plain terms (2.5.1)</p> <p>I watched a few surgeries on You Tube as well in kind of... not in a morbid sense but I needed to see what happened. (2.5.1, 2.5.3, 2.5.5)</p>	<p>A lot of people aren't as lucky as me don't get funding for the strips so every time you use one it's about 75p. To buy a bottle of 100 strips is a lot of money if you need that every two weeks it can be a lot of money for people and the actual machine costs 400 pounds so it's a big chunk of money.</p>	<p>Give me 10 years I might be static but until then the body is always changing and then there is new challenges because you know I'm on two things which prevent pregnancy so give me ten years till I'm 30 and I'll be thinking about kids and that means a whole new set of research and a whole new set of understanding that I haven't even begun to think about yet. (2.7.9 , 2.7.10)</p>	
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Framework chart for health literacy categories – cardiac rehabilitation group

Participant (interview)	2.1 Functional	2.2 Interactive (person to person)	2.3 Critical	2.4 Scientific	2.5 Interactive media	2.6 Civic	2.7 Risk	2.8 Distributed
<b>Participant 5 (1)</b>		<p>whenever we have talked about it it's been a conversation between the two of us and a kind of exchange of information really rather than just him telling me things. (2.2.1)</p> <p>we discussed that and he says well we'll go through what he prospects were and what I should be doing and things like that (2.2.1)</p> <p>Um I actually got the information off the internet and took it into him that kind of thing. He then went onto the website and got more information for himself sort of thing (2.2.3)</p>			<p>If I'm looking for information say on heart surgery I just type in heart surgery on Google and see what comes (2.5.1)</p> <p>I find it confusing actually because if you read two or three different articles they tell you completely different things but I think you just try and put together things that you can actually identify with yourself and um that's it basically (2.5.2, 2.5.3)</p> <p>Um I actually got the information off the internet and took it into him that kind of thing. He then went onto the website and got more information for himself sort of thing (2.5.1, 2.5.3)</p>		<p>How it happened I don't know because I was eating a particularly bad diet or....i kept myself really fit and that so it's no real pointers to what he risk factors are for the future even so. My cholesterol was slightly high um it wasn't majorly high it was just slightly high and that's been brought down now. (2.7.1)</p> <p>I was aware of the risks um but I didn't think they would particularly apply to me because I thought everything was under control you know and my diet was reasonably I suppose I've changed my diet slightly um I tried to make sure I don't eat too many biscuits. (2.7.1)</p>	
<b>Participant 5(2)</b>					<p>Sometimes you get misled as well when you try and do it yourself you know. Especially if you do it on the internet you get so many different things coming to you (2.5.1, 2.5.2., 2.5.3)</p>		<p>Um I think it probably has I think it's made me more aware of the um possibility of having things like heart attacks and what have you (2.7.10)</p>	
<b>Participant 5(3)</b>		<p>When I first went on to beta-blockers for high blood pressure I kind of discussed it with the doctor and you know we decided.... I took his advice basically but I was aware that there was a variety of different medications. (2.2.1)</p>			<p>I have gone on to the internet and researched the actual condition and that. (2.5.1)</p>			

Appendix 11  
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### *Design of the framework approach*

